

Engaging Older Adults with Age-Related Macular Degeneration in the Design and Evaluation of Mobile Assistive Technologies

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Doctor of Philosophy (by Research)

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Thesis Summary

Ongoing advances in technology are undoubtedly increasing the scope for enhancing and supporting older adults' daily living. The digital divide between older and younger adults, however, raises concerns about the suitability of technological solutions for older adults, especially for those with impairments. Taking older adults with Age-Related Macular Degeneration (AMD) – a progressive and degenerative disease of the eye – as a case study, the research reported in this dissertation considers how best to engage older adults in the design and evaluation of mobile assistive technologies to achieve sympathetic design of such technologies.

Recognising the importance of good nutrition and the challenges involved in designing for people with AMD, this research followed a participatory and user-centred design (UCD) approach to develop a proof-of-concept diet diary application for people with AMD. Findings from initial knowledge elicitation activities contribute to the growing debate surrounding the issues on how older adults' participation is initiated, planned and managed. Reflections on the application of the participatory design method highlighted a number of key strategies that can be applied to maintain empathic participatory design rapport with older adults and, subsequently, lead to the formulation of participatory design guidelines for effectively engaging older adults in design activities. Taking a novel approach, the final evaluation study contributed to the gap in the knowledge on how to bring closure to the participatory process in as positive a way as possible, cognisant of the potential negative effect that withdrawal of the participatory process may have on individuals. Based on the results of this study, we ascertain that (a) sympathetic design of technology with older adults will maximise technology acceptance and shows strong indicators for affecting behaviour change; and (b) being involved in the design and development of such technologies has the capacity to significantly improve the quality of life of older adults (with AMD).

Keywords: age-related macular degeneration, older adults, user-centred design, participatory design, mobile assistive technology, diet diary.

Dedicated to my family: Mesrop, Nazeli and William.

Acknowledgements

I have been fortunate enough to undertake Ph.D. research that transformed my professional aspirations into personal inspirations and stimuli; while challenging at times, my journey has been extremely rewarding and satisfying, and for that I am most grateful. I would therefore like to extend my immeasurable appreciation and deepest gratitude to the following persons, who in one way or another have contributed in making this wonderful journey possible.

Foremost, I would like to extend my gratitude to Dr. Jo Lumsden – my wonderful supervisor whose selfless time and care were sometimes all that kept me going; who – knowingly and unknowingly – led me to an understanding of some of the more subtle challenges to our ability to thrive, and whose maddening attention to detail drove me to finally learn to scrutinise my writing. Thank you for the deft ways in which you sympathetically challenged and supported me, knowing when to push and when to let up. Thank you for keeping a sense of humour when I had lost mine; thank you for being the best supervisor possible – you could not even realise how much I have learned from you!

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Most importantly I’d like to thank my wonderful children Naz and Will, and my husband Mesrop Levyan, for supporting me in my determination to find and realise my potential, without whom this dissertation would never have been completed. A very special thank you to you all for your practical and emotional support, as I added the roles of wife and mother to the competing demands of study, work, and personal development. You have cheered me on and done your best to keep me sane with your unconditional and undeterred love and support. Thank you for nurturing me through the months of writing and for putting up with my Ph.D. life schedule!

Finally, the biggest thanks of all go to my wonderful participants for volunteering their time, and sharing their stories and experiences with me. Without my participants this research would never have been possible and to them I am incredibly grateful. I would have liked to name and individually thank each of them, but to preserve confidentiality I will not.

Publications Arising from this Thesis

- **Hakobyan L.**, Lumsden, J., O'Sullivan, D., & Bartlett, H., (2012) *Understanding the IT-Related Attitudes and Needs of Persons with Age-Related Macular Degeneration: A Case Study*, in Proc. of BCS-HCI '12, Birmingham, UK, Sept 12-14, 239-244.

This paper presents findings from our knowledge elicitation activities.

- **Hakobyan L.**, Lumsden, J., & O'Sullivan, D., (2013) *PICTIVE Participatory Design Process with Older Adults with AMD*, in Proc. of iHCI' 13, Dundalk, Ireland, June 12-13.

This paper reports on our experience of adopting and adapting the PICTIVE PD approach to inclusively create paper prototype designs of the diet diary application. It also reports on participants' reflection on being part of the process, and the emergent design themes identified.

- **Hakobyan L.**, Lumsden, J., & O'Sullivan, D. (2013) *Designing a Mobile Diet Diary Application with and for Older Adults with AMD: A Case Study*, Proc. of BCS-HCI '13, London, UK, Sept 9-13. 1-10.

This paper reports on the outcome of the PD sessions – that is, a paper prototype of our proposed application – and discusses implications for the eventual prototype development.

- **Hakobyan, L.**, Lumsden, J., O'Sullivan, D., & Bartlett, H., (2013) Mobile Assistive Technologies for the Visually Impaired, *Survey of Ophthalmology*, 58(6), 513-528.

This was a major review reporting on the landscape of assistive technology specifically designed for individuals with visual impairments. It was in the top 10 most downloaded articles from the journal in 2014.

- **Hakobyan, L.**, Lumsden, J., & O'Sullivan, D., (2014) Older Adults with AMD as Co-Designers of an Assistive Mobile Application, *International Journal of Mobile Human Computer Interaction (IJMHCI)*, 6(1), 54-70.

This paper is an extended version of the paper above entitled “*PICTIVE Participatory Design Process with Older Adults with AMD*”: we were invited to extend the aforementioned paper for publication in the International Journal of Mobile Human Computer Interaction.

- **Hakobyan L.**, Lumsden, J., & O'Sullivan, D. (2014) *Co-Designing a SMART Diet Diary Application with Older Adults with AMD*, in Proc. of BCS-HCI '14, Southport, UK, Sept 9-12.

This paper provides an overview of our PD activities and the development of the application: it is reported as a case study in order to outline the practicalities and highlight the benefits of participatory research for the design of sympathetic technology for (and importantly with) older adults with impairments.

- Nicol, E., Dunlop, A., Komninos, A., McGee-Lennon, M., Baillie, L., Edwards, A., Eslambolchilar, P., Goodman-Deane, J., **Hakobyan, L.**, Lumsden, J., Mulder, I., Rau, P., & Siek, K. (2014). *Re-Imagining Commonly Used Mobile Interfaces for Older Adults*, Proc. of the 16th International Conference on Human-Computer Interaction with Mobile Devices (MobileHCI '14), Toronto, ON, Canada, ACM: 585-58.

This is a workshop position paper reflecting a workshop (for which the author was an organiser) which aimed to bring together researchers from a wide range of disciplines – who are re-imagining common mobile interfaces so that they are more suited to use by older adults – to discuss and enhance activities to push this domain forward within the wider MobileHCI community.

- **Hakobyan L.**, Lumsden, J., & O'Sullivan, D. (2014) *Participatory Design with Older Adults for Healthcare Apps*, in Proc. of the Workshop on Re-imagining Commonly Used Mobile Interfaces for Older Adults, part of the 16th International Conference on Human-Computer Interaction with Mobile Devices (MobileHCI '14), Toronto, ON, Canada, Sept 23-26.

This paper reports on lessons learned from adopting and adapting PD approaches, generalising findings for the design of healthcare applications for older adults. The paper received the Workshop Best Paper award.

- **Hakobyan, L.**, Lumsden, J., & O'Sullivan, D., (2014) Participatory Design: How to Engage Older Adults in Participatory Design Activities, *International Journal of Mobile Human-Computer Interaction (IJMHCI)*, 7(3), 78-92.

We were invited to extend the above paper ("*Participatory Design with Older Adults for Healthcare Apps*") for inclusion in the Special Issue of Best MobileHCI'2014 Workshop Papers.

- Lumsden, J., **Hakobyan, L.**, Leung, R. & O'Sullivan, D., (accepted 11 Apr 2014: in press) *Inclusive Participatory Design: Involving Users with Disabilities in the Design of Assistive Technologies*. to appear in Encyclopedia of Computer Science and Technology Taylor and Francis.

This paper explores some of the challenges associated with including individuals with disabilities in the participatory design of assistive technologies, and presents a collated set of generalised guidelines (reflecting on their application) for inclusive participatory design.

Presentations/Talks Delivered

The research presented talks at the respective conferences for all of the above conference papers. In addition, she presented the following:

- **Hakobyan L.** 2013. *SMART: Self-Monitoring Ability Reactive Technology for Older Adults with AMD*. In: Doctorial Consortium of 15th International Conference on Human-Computer Interaction with Mobile Devices and Services, MobileHCI 2013, Munich, Germany, 27-30 August 2013.

The researcher won a place in the prestigious doctoral consortium of the premier international conference on Mobile HCI (MobileHCI'2013), and reported on the knowledge elicitation and participatory design activities.

- **Hakobyan L.** 2014. *Developing a Diet Diary Application for and with Older Adults with AMD*. In: Doctorial Consortium of Proc. of BCS-HCI '14, Southport, UK, 9-12 September 2014.

The researcher won a place in the doctoral consortium of the BCS-HCI '14 Conference, and reported on the design and development phases of the project.

- **Hakobyan L.**, Lumsden, J., & O'Sullivan, D. 2014. Poster at the ARCHA Healthy Ageing, Facilitating Research through International Partnership Symposium, Birmingham, UK, 15-18 July, 2014.

This poster reported on findings from knowledge elicitation and design activities, and introduced the diet diary application design.

- **Hakobyan L.**, Lumsden, J., & O'Sullivan, D. 2015. Participatory Design Process with Older Adults with AMD. IAGG-ER 2015 Congress, Dublin, Ireland, 23-26 April 2015.

This talk reported on our participatory design activities, and reflected on how the method could be adopted and adapted to collaborate with older adults (with different impairments) in general.

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Chapter 1. Introduction

1.1 Research Motivation

The global population of people aged 60 years and older is growing rapidly; it is estimated that the proportion of the world's population over 60 years of age will reach 22% by 2050 (WHO, 2014). Healthcare reforms aimed to address our ageing population, increasing levels of chronic disease, and consequently soaring healthcare costs, propose a new model of future healthcare delivery, wherein patients care for themselves and take more responsibility for their own healthcare in their own homes in an attempt to efficiently moderate healthcare costs without impairing healthcare quality (Nobel and Norman, 2003; Anderson and Horvath, 2004). For such a paradigm shift to be realised, the supporting healthcare technology must address the needs of older patients efficiently and effectively to ensure technology acceptance and use (Anderson and Horvath, 2004; Carroll *et al.*, 2002). Ongoing advances in information technology (IT) are undoubtedly increasing the scope for supporting the delivery of healthcare to older adults within their homes via assistive technologies. Unfortunately, however, age-related physical and sensory impairments – many of which change or degenerate over time – are common amongst older adults and present a number of design and ethical challenges in terms of the successful and effective development of such technologies.

With around 285 million people worldwide (WHO, 2014) and almost 2 million people in the UK (RNIB, 2015) living with sight loss, visual impairment is one of the most serious age-related health concerns among older adults (Crews, 2003; Eye Diseases Prevalence Research, 2004). The most common cause of sight loss in the UK is Age-Related Macular Degeneration (AMD); typically affecting people aged 50 and above, it impacts nearly one in ten of those over 80, and accounts for 16,000 blind/partial sight registrations per year (RNIB, 2015). AMD is also the leading cause of blindness among people aged 55 years and older in the U.S.A and other Western countries (Bressler, 2004; Chakravarthy *et al.*, 2010). As a progressive, degenerative disease of the eye it severely affects the macula, located at the centre of the retina, which is vital for clear central vision. As highlighted by Figure 1.1, AMD presents a significant challenge in terms of user interface (UI) design for technology – a challenge which is further complicated by the degenerative nature of the disease.



Figure 1-1: *Example of how an image might be viewed through an eye affected by AMD at various stages of the disease [generated using www.inclusivedesigntoolkit.com].*

Generally, the progress of the disease is slow and peripheral vision is usually retained (Mitchell and Bradley, 2006). In most cases, people with AMD have “dry” AMD where pigment and light detection cells in the retina die off and the person experiences gradual loss of central vision. With some people this can, however, progress to “wet” AMD where the blood vessels leak fluid, bleed, scar and result in rapidly reduced central vision (Klein *et al.*, 1995): in the UK, advanced AMD impacts 4.8% of those aged over 65 and 12.2% of people aged 80 and above (Macular Society, 2015). AMD significantly limits the independence of

elderly patients as a result of the increased challenges associated with completion of daily activities (Cahill *et al.*, 2005) and reduces their quality of life (Mitchell *et al.*, 2008).

There is evidence that there is a link between dietary factors, AMD risk (Beatty *et al.*, 2001), and AMD progression (AREDS, 2013). The landmark Age Related Eye Disease Study (AREDS) showed that patients with high risk characteristics for AMD can lessen their risk of developing advanced AMD by taking appropriate nutritional supplements. It has been estimated that, of the 8 million people in the U.S.A. who are considered to be at high risk of developing AMD, 1.3 million would be likely to develop advanced AMD if no treatment with the AREDS supplements were given (AREDS, 2013).

Unfortunately, however, risk factors such as diet are not easily measured in routine clinical practice (Chong *et al.*, 2008; Seddon *et al.*, 2007) and little guidance – and certainly not guidance that is customised to the individual – is currently available to people with AMD in terms of dietary adjustments that might positively impact the risk or rate of progression of the disease.

Given the above, it is important to encourage persons at risk to maintain a diet high in specific nutrients such as carotenoids (AREDS, 2013). Electronic diet diaries have proven to be successful aids for improving independent living and care in fields such as diabetes (Tsang *et al.*, 2001) and weight control (Yon *et al.*, 2007); various electronic diet diaries are already available on mobile platforms – e.g., Fit4Life (Purpura *et al.*, 2011), Health and Diet Manager (Softpedia, 2015), etc. – but fall short of identified needs for an AMD audience in a number of ways. They present visually-intensive UIs which are not adapted to people with visual impairment and do not support independent, accurate, and convenient use by users with AMD. Further, existing systems do not make AMD-specific dietary recommendations customised for individual users based on their data or preferences.

Designing assistive technologies that are effective and meet with end user acceptance for individuals with degenerative impairments such as AMD demands a good understanding of

the needs and abilities of target users. This is complex given that a range of aspects of users' cognitive, physical, and sensory capabilities need to be taken into account, in addition to users' attitudes towards both technology and their own disability, as such attitudes often influence their technology acceptance (e.g., Hwang, 2012). While such degenerative impairments associated with ageing (Heart and Kalderon, 2013) and age itself can essentially make technologies much harder to use (Hawthorn, 2000), studies have identified counter-intuitive interfaces and unfamiliarity with computers as significant barriers for the use of technology by older adults (e.g., Czaja *et al.*, 2006). Perhaps the biggest limitation of technology use by the elderly is the fact that such technologies are not typically specifically designed to meet older adults' needs, wants and capabilities (e.g., Sayago and Blat, 2010; Leonardi *et al.*, 2008), despite the advances, for instance, in the field of gerontechnology (e.g., Leonardi *et al.*, 2008) and in approaches such as universal and inclusive design (e.g., Dix, 2010) which encourage designs that better consider the needs of users such as the elderly and the disabled. Nevertheless, research on methodological best practice for working with older adults with AMD is scarce: persons with AMD have not traditionally been directly involved in the design of technology to support their needs.

1.2 Research Questions and Objectives

Grounded on the issues outlined in the previous section, the aim of this research was to develop an assistive mobile application – a bespoke diet diary – for accurately and conveniently recording diet information and automatically providing customised dietary recommendations to empower ageing persons with AMD to make informed dietary choices that could lead to retardation of the progression of the disease. Taking a multidisciplinary approach, this applied research placed strong emphasis on the methodological process necessary to achieve an effective assistive technology solution for individuals with AMD from which generalised methodological knowledge and recommendations can be extracted. As such, the main research questions were:

1. *What constitutes effective practice in terms of engaging older adults with AMD (and more generally) in user-centred, participatory research for assistive technology design and development?*
2. *What do older adults with AMD need and expect in terms of an assistive mobile technology to manage their dietary health associated with AMD disease progression and what indicators are there that an application designed to meet such needs and expectations affects dietary behaviour change?*
3. *How should the acceptability and impact of a diet diary for persons with AMD be evaluated in order to identify use patterns and psychological factors that predict behaviour change in response to the dietary recommendations?*
4. *What constitutes best practice in terms of bringing closure to participatory research in as positive a way as possible for older adults?*

1.3 Research Approach

This research adopted a novel, multidisciplinary approach between computer science, psychology, and clinical optometry in order to deliver a technological solution that considered the design, sensory modality, and placement of user interface (UI) elements such that it can be used effectively and independently by persons with AMD. Taking a blended philosophical stance, this research adopted user-centred design (UCD) and participatory (PD) approaches for the inclusion of target users throughout all stages from the design to deployment of the application to facilitate their needs, difficulties and viewpoints. UCD is a multi-stage philosophical approach to technology design that places the user at the centre of the design process. The main characteristic of UCD is that it attempts to optimise a product around user needs, abilities and desires (rather than forcing the users to change their behaviour to suit the product) by placing them at the forefront of a designers mind. PD, on the other hand, shifts the notion from designing *for* users (i.e., the notion of UCD) to one of designing *with* users (Sanders, 2002); and refers to a democratic approach to technology design that calls

for end-user involvement in the design process, in which end users are actively established and empowered as co-designers in the process.

This research embraced a qualitative approach to collecting and analysing rich subjective research data from older adults with AMD with diverse backgrounds in order to ensure a broad and inclusive picture of user needs as they relate to the design of assistive technologies. This research utilised various tried-and-tested UCD methods for collecting and analysing research data, including: questionnaires; semi-structured interviews; in-home observational studies; focus groups; participatory design; and longitudinal field study-based evaluation. Adopting and adapting a range of UCD tools and methods proved beneficial in terms of minimising challenges associated with enabling target users to effectively participate in the design and development of technology to meet their needs. Qualitative data analysis was adopted to identify and analyse patterns (themes) within collected data.

The work presented in this dissertation followed seven main phases of exploration, design, development, and evaluation, with each phase building upon the knowledge gathered in the previous phases. These phases are discussed in more detail in the following subsection.

1.4 Thesis Structure

Chapter 2 presents the important concepts underpinning this research problem via a review of relevant scientific literature. First, the chapter provides an overview of assistive, persuasive, and adaptable technologies. Next, all aspects of mobile assistive technologies for the visually impaired people are explored: discussion reflects on research which has been done to make standard mobile hardware more accessible to people with vision loss (e.g., mobile phones). Research which uses mobile devices as a platform for delivery of specialised assistive support is then considered, with associated discussion highlighting innovation in navigation and wayfinding support, obstacle detection, space perception, independent shopping, and smart homes and robotics. Thereafter, research into assistive technologies specifically for people with AMD is reviewed. The focus then shifts to design approaches to assistive technologies for older adults in general, providing an overview of the

research in the areas of accessibility and universal design, UCD, and participatory design (PD) approaches. The final section of Chapter 2 reviews previously known older adults' attitudes toward technology that may influence users' acceptance of and motivation to use an assistive technology.

Chapter 3 reports on our knowledge elicitation activities (research phases 1–3), highlighting the methods used and their adaptation to support our target user participation. It reflects on how user participation was planned and managed in order to appreciate the impact that technology may have on users as well as to inform the design and structure of the proposed technical solution: in particular, the discussion focuses on how the participatory research was initiated (i.e., how we addressed issues such as establishing relationships with communities/participants and determining the research context) and how focus groups and in-home observational studies were adopted to collect qualitative ethnographic data about the needs and views of older adults with AMD; it concludes with a reflective discussion on how the process was managed to encourage ongoing participation and user engagement (for subsequent stages of the project), and in so doing better understand methodological practice.

Chapter 4 reports on how the PICTIVE (Muller, 1991) PD approach was adopted to inclusively create paper prototype designs of the proposed application for users with AMD to support their dietary-based AMD progression retardation over time. In reporting on the design activities conducted for the purpose of informing the development of the application (research phase 4), it focuses on the tangible outcomes (in essence, prototypic designs and identified user requirements) of the process. Finally, participants' reflections on being part of the process and findings from preliminary evaluations of the paper prototype design are also discussed.

Chapter 5 reflects on the experience of adopting and adapting a UCD participatory design approach to support effective design with and for our special needs user group. It reflects on

participants' views of being part of the research process, discusses the design themes emerging from the PD activities, and suggests recommendations for (or further insight into) how direct involvement of special needs users might be successfully achieved with relatively easy adaptation and/or accommodation of standard design practices. A series of themes and guidelines extracted from the experience are also presented.

Chapter 6 introduces the final interface design and functionality included within our prototype diet diary application. It also discusses and reflects on the process by which the application was implemented in Android in order to raise awareness of the contradictions that exist between user interface (UI) design requirements as dictated by special needs users and technical mobile development platforms and norms catering to the masses.

Chapter 7 details the research design and methods used to conduct two phases (research phases 5 and 6) of a usability evaluation study that was conducted to collect empirical data to support investigation of the usability, acceptability and initial impact indicators of the prototype application. Analysis of the data is also documented in this chapter.

Chapter 8 first reports on a focus group-based study (research phase 7) aimed to address a methodological knowledge gap in the field of HCI concerning how best to 'end' participatory research. It then reflects on how guidelines for inclusive design practice have been applied throughout the research study to support the application's design, development and evaluation process; thereafter, an enhanced and extended version of the guidelines for working with older adults (with AMD) is presented.

Finally, Chapter 9 outlines the conclusions, contributions to knowledge, and future research directions arising from this research.

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Chapter 2. Background Literature Review

2.1 Introduction

With more than 500 million people around the world with some form of recognised disability associated with a mental, physical or sensory deficiency (Plos *et al.*, 2012), there is considerable scope for IT-based assistive technologies to enhance the independence and quality of life for many. To achieve this potential, however, requires researchers to invest time and effort in familiarising themselves with the domain of, and the needs and specific capabilities of target users with, given disabilities – a challenging task (Slegers *et al.*, 2013). In recognition of the requirement to be better able to understand user needs as they relate to assistive technologies in order to advance such technologies (Eghdam *et al.*, 2012), researchers are calling for the direct involvement of individuals with disabilities and other key stakeholders in user-centred design processes as well as the need for more systematic approaches to inform such processes (Eghdam *et al.*, 2012; Hwang, 2012).

The recent past has also seen the emergence of specialist centres, such as Dundee University's 'User Centre', which engage older adults in research and development of technological solutions based on their needs and wants (Forbes *et al.*, 2009). Furthermore,

the advent of mobile devices has led to increased research into making mobile devices more accessible to older adults. For instance, icon usability issues (and suggestions for enhanced design) for older adults has been researched in terms of size (Siek *et al.*, 2005), colour/contrast (Hawthorn, 2000) and other characteristics (e.g., presence of labels (Leung *et al.*, 2011)). Similarly, Leung *et al.* (2010) suggested improving the *learnability* (Nielsen, 1996) of mobile device applications for older adults via a Multi-Layered (ML) interface approach: that is, users are initially introduced to the 'reduced-functionality'/'simplified' layer before learning to perform more advanced tasks.

With the rise of touchscreen (mobile) technologies, researchers have also explored the accessibility of this technology for older adults. As part of the Building Bridges project (which itself is part of a wider programme of research within the Technology Research for Independent Living (TRIL) Centre) a touchscreen and stand-alone communication device was developed to facilitate older adults' social interaction (Doyle *et al.*, 2010). A user-centred design approach was adopted to understand older adults' unique needs and motivation for using technology. The aim of the device was to provide older adults with an opportunity to connect with their family and friends via individual/group calls, a messaging service or chat forum. Results from evaluation of the device with older adults revealed that participants' personal perception of the value of technology to them is of utmost importance for any technological device to be accepted and used in the long term. This further reinforces the importance of taking into account older adults' cognitive and sensory impairments arising as a result of ageing when designing for this user group.

This chapter outlines the important concepts underpinning this research problem via review of relevant scientific literature. Section 2.2 provides an overview of relevant assistive, persuasive, and adaptable technologies. Next, in Section 2.3, all aspects of mobile assistive technologies for the visually impaired people are explored: discussion reflects on research which has been done to make standard mobile hardware more accessible to people with vision loss (e.g., mobile phones). Research which uses mobile devices as a platform for

delivery of specialised assistive support is then considered, with associated discussion highlighting innovation in navigation and wayfinding support, obstacle detection, space perception, independent shopping, and smart homes and robotics. Thereafter, in Section 2.4, research into assistive technologies specifically for people with AMD is reviewed. The focus then shifts to design approaches to assistive technologies for older adults in general, providing (in Section 2.5) an overview of research in the areas of accessibility and universal design, UCD, and participatory design (PD) approaches. The final section of this chapter reviews previously known older adults' attitudes toward technology that may influence users' acceptance of and motivation to use an assistive technology.

2.2 Assistive Technology: Goals and Interpretations

Assistive technologies are in widespread use and their benefits are well documented (e.g., Hersch, 2010; Scherer and Lane, 1997; Phillips and Zhao, 1993). Such technologies have evolved significantly over the years, from a simple typewriter built in the 19th century to help blind people write legibly (Magar, 2011) to a mobile phone application helping visually impaired individuals to 'see' and understand their surroundings (Liu *et al.*, 2010). Assistive technologies have the potential to enhance the quality of life of visually impaired persons via improved autonomy and safety; furthermore, by encouraging them to travel outside their normal environment and to interact socially by independent means these technologies can decrease their fear of social isolation (Cattan *et al.*, 2005).

There are various definitions of the umbrella term '*assistive technology*': common to them all, however, is the concept of an item or piece of equipment that enables individuals with disabilities to enjoy full inclusion and integration in society (Foley and Ferri, 2012; Mountain, 2004; Scherer, 1996). Traditional assistive technologies include long canes, walkers, etc; IT-based assistive technologies include screen magnifiers and readers, etc., while modern mobile IT-based technologies are more discrete, and include (or are delivered via) a wide range of mobile computerised devices (including ubiquitous technologies like mobile

phones). It is widely recognised that such discrete technologies can help alleviate problems related to ‘cultural stigma’ that are often associated with the more traditional (and obvious) assistive devices (Pocklington Trust, 2003).

In this review, the terms “*mobile assistive technology*” and “*assistive technology*” are used interchangeably to refer to mobile IT-based solutions and/or enhancements for facilitating the independence, safety and overall improved quality of life of individuals with visual impairment (Mountain, 2004). This stated assistive technology focus by no means restricts the focus of the review to assistance provided via small mobile platforms; as discussed in more detail in the following section, this view of assistive technology extends to include robotics as well as the accumulation of co-located and embedded technologies to create smart homes (as discussed in Section 2.3.2).

2.2.1 Persuasive Technology

Taking into account the potential cognitive (e.g., dementia, aphasia), sensory (e.g., hearing and visual impairments) and physical (e.g., arthritis) limitations of older adults, effective design of technology for older adults to sustain their independent living and quality of life often draws on the concept of persuasive technology. Research has explored the use of persuasive technologies for motivating people to change their attitudes/behaviours by drawing on theories of behaviour and behaviour change (Fogg, 2002). Such technologies encapsulate manifestations of psychological models such as the Theory of Planned Behaviour (TPB), which relates to planned behaviour, that is, predicting intention; the model suggests that intention is dependent on attitudes, subjective norms and perceived behavioural control, but that behaviour is directly impacted by intention and perceived behavioural control (PBC) only. (Ajzen, 1991). TPB states that behaviour is guided by behavioural beliefs (e.g., what are the consequences of using a particular technology?), normative beliefs (e.g., what do others think about the use of particular technology?), and control beliefs (e.g., external factors that may facilitate or impede the use of technology)

(Ajzen, 1991). The intention is to design technological solutions that support users in transforming their health behaviours in order to increase their wellbeing (IJsselstein *et al.*, 2006; De Kort *et al.*, 2005). Examples of such systems to date include support for smoking cessation (Räsänen *et al.*, 2008) weight control (Purpura *et al.*, 2011) and improved social interactions (Kass, 2007), amongst others.

One of the behaviour change models that most directly applies to the technology use and design is the Fogg Behaviour Model (FBM), which suggests that behaviour change is contingent to the following three elements: Motivation, Ability, and Trigger (Fogg, 2009). It argues that for a person to perform a target behaviour (e.g., use assistive technology), he or she must be “sufficiently motivated” (e.g., what are the perceived benefits of using such technology?), “have the ability to perform the behaviour” (e.g., are users capable of using technology?), and “be triggered to perform the behaviour” (e.g., make use of reminders/notification to encourage the use of technology) (Fogg, 2009, p.1). A well-designed technological solution would have many sources of motivation and triggers (these could be technology-enabled and/or perhaps have self-monitoring, goal setting or competitive features), and would be reasonably simple to use to increase users’ ability to perform certain behaviour.

It has been long advocated, that an effective strategy for supporting users in changing their behaviours is by employing goal-setting in persuasive technologies (e.g., Strecher *et al.*, 1995; Locke and Latham, 2002); and one theory that is commonly adopted for the design of healthy lifestyle interventions that supports users in transforming their health behaviours, is the Goal Setting Theory proposed by Locke and Latham (2002). They argue that people perform best when they are committed to their goals, and this is particularly true when goals are somewhat challenging. Two key factors facilitating goal commitment include the importance of goal attainment to the individual (including what outcomes they expect as a result of attaining a goal); and self-efficacy (i.e., their belief that they can attain the goal) (Locke and Latham, 2002). To increase the importance of a goal attainment for an individual,

it is recommended to encourage the individual to make a public commitment to achieving the goal, or provide an incentive (the rate of which is an important consideration for maintaining optimum performance). Additionally, people need summary feedback on their performance to compare their progress to their goals, in order to adjust the level of their effort required for achieving their goals. A further important consideration is the source of the goal; that is, is the goal (1) self-set (this relates to self-efficacy – individuals are more likely to set a goal that they believe can be realistically achieved; (2) participatory set (individuals who participate in setting goals, tend to set higher goals and have higher performance); or (3) assigned (which can lead to lower performance without a well-reasoned explanation) (Locke and Latham, 2002). When applying Goal Setting Theory to the development of persuasive technologies, it is advocated that the goal is set by the user or participatively (with an expert), to ensure that the goal is important to target users. While challenging, the goal should be realistically attainable; and the user should receive incentives and feedback both on their progress and when the goal is attained (Consolvo *et al.*, 2009a). One of the limitations of the theory, however, is its failure to specify the effect of the subconscious on action (i.e., when people perform a behaviour without being attentive to what is motivating them) (Locke and Latham, 2004).

An example of persuasive technology designed by employing theory driven design strategies (Consolvo *et al.*, 2009b) is 'Fit4Life' (Purpura *et al.*, 2011), which promotes 'healthy behaviour' and 'ideal weight' by stimulating new behaviours by making them 'simpler' (Fogg, 2002) and introducing rewards and motivations (Torning and Oinas-Kukkonen, 2009). The system consists of the 'Fit4Life' iPhone application and a series of sensors and components operated by the application, namely: a data recorder for estimating the calories of food consumed; an earpiece as a Bluetooth receiver (which also measures jaw movements to track eating behaviour); an electronic scale that can be inserted into the user's sock or shoe; a heart rate monitor to determine exercise behaviour; a metabolic lancet worn on a toe for analysing blood to determine current metabolic rate; and a support cloud

implemented as a connector to social networking sites to broadcast the user's progress. The initial phase of use of the application is an 'Assessment and Configuration' phase whereby the user's BMI and a correct diet and fitness plan are determined based on the user's height and age. The system then 'persuades' the user to achieve a BMI in the ideal range by employing persuasive design principles including 'self-monitoring', 'tunnelling', 'tailoring', 'personalisation' and 'social comparison'. The principle of 'self-monitoring', for instance, is implemented by allowing users to monitor their performance related to metrics relevant to achieving their goal. The 'social comparison' strategy is instigated by assigning each user to a monitored treatment group on Facebook, where users' progress is updated against their personal goals such that they can either be praised when their eating and exercise behaviour is in balance, or else encouraged by other users to keep on track. At time of writing, user trials are planned to evaluate the system efficacy; the designers also aim to encourage other designers of persuasive technology to reflect on the social, ethical and political issues that such technology may raise.

Although designers of persuasive technologies often draw from psychological theories on how behaviour is influenced (e.g., Locke and Latham, 2002), Kaptein *et al.* (2011) urge designers of persuasive (and adaptive) systems to seek user involvement when determining which strategy a system should best utilise. Designing persuasive technology for older adults by employing user-centred design approaches is a relatively under-researched area, but Romero *et al.* (2010) did follow such a process (involving various stakeholders via interviews, focus groups, usability and field studies, etc.) to develop a sound understanding of older adults' needs and preferences as they relate to the development of playful persuasive mechanisms such as 'curiosity', 'exploration' and 'nurturing' in order to encourage older adults to engage in social and physical activities in a care home. Their user-centred approach also contributed towards a realisation of how persuasive technology can best be introduced to older adults. Romero *et al.* implemented the *Activator* – essentially, the care home's traditional activity leaflet enhanced with a digital display to provide interactivity and supplementary information; users are informed about opportunities for physical and social

interaction in the care home via a shining light on the leaflet which works as a curiosity technique to persuade users to look for further information. The *Activator* also supports self-monitoring via the use of sensor networks and information management so that users can monitor their own physical and social activity performance on a daily basis. Furthermore, to study the effects of 'nurturing', the *Activator* allows users to set and visualise performance goals. It also maintains 'curiosity' and 'exploration' by making users' personal information available on displays in shared rooms (e.g., coffee rooms) such that users can compare their performance against others or perhaps find out who is planning to attend which activity. Based on their findings, Romero *et al.* (2010) identified three components that are important in the design of persuasive mechanisms to support older adults to be more socially and physically active – namely, design for transitions, use of mutual motivators, and playful persuasive mechanisms. Additionally, they proposed the following initial set of recommendations for the design of persuasive mechanisms for older adults: (1) modular and flexible solutions are important for enabling people to evolve different uses over time; (2) playful persuasive components offer motivating mechanisms while evoking a fun experience; and finally, (3) they recommend the development of familiar and tangible designs with simple interfaces with which older adults can interact. At time of writing, Romero *et al.* reported planning longitudinal field studies to evaluate *Activator*, including investigating users' privacy concerns regarding sharing performance information with others and assessing if behaviour change among participants can be observed.

Despite recent substantial advances in research into the design, more generally, of assistive technology for the ageing population, the design of *persuasive* technology for older adults remains a relatively under-researched area. None of the reviewed systems/solutions appear to consider the age-related physical and sensory impairments that older adults are likely to experience or the continual changes they may experience in their condition or environment over time. Consequently, there still exist many design and ethical challenges related to designing persuasive technology for this user group.

2.3 Assistive Technology for People with Visual Impairments

This section discusses research into assistive technology that has been specifically designed for visually impaired people and, in so doing, illustrates the unique needs of this user group that must be considered when designing technology for their use. Visual loss, unfortunately, inevitably leads to impaired ability to access information and perform everyday tasks (Binns *et al.*, 2012). In today's knowledge intensive society, information access is increasingly crucial, not just for performing daily activities but also for engaging in education and employment. As such, for a visually impaired person, a key function of many assistive technologies is also to provide access to information (Pal *et al.*, 2011). Information accessibility for people with visual impairment has been enhanced in a general sense by the development of tactile- and auditory-based presentation methods as effective alternatives to traditional visual presentation of information (Abu Doush and Pontelli, 2010; Ahmed *et al.*, 2010; Moskovitch and Walker, 2010; Edwards *et al.*, 2015). These alternative modalities for information access are, for example, applicable to websites (Mahmud and Ramakrishnan, 2012; Petrie *et al.*, 2013), charts and graphs (e.g., Abu Doush and Pontelli, 2010; Ferres *et al.*, 2010; Moraes *et al.*, 2014), shapes (Safi *et al.*, 2015), reading text (Yi and Tian, 2015) and facial expressions (e.g., Bala *et al.*, 2010). It should also be noted, that VoiceOver, introduced by Apple in 2005, was a significant contribution to the advancements in access to information for users with visual impairments. Unlike other screen readers (e.g., Windows Narrator), VoiceOver was the first fully functional screen reader build into an operating system that didn't require additional installation procedures (AVAppleVis, 2015).

The advent of mobile phones, in particular smartphones, has piloted a new era of connectivity where users are afforded instant information access (Billi *et al.*, 2010). Such devices are no longer just telephony devices but now offer an impressive cluster of features in a compact, portable form factor (Liu *et al.*, 2010). Accordingly, a growing number of individuals who are visually impaired are using smartphones in their daily activities (Krishna and Panchanathan, 2010). A fundamental advantage of using mobile devices to deliver assistive technologies is the unobtrusive nature of many of the delivery platforms; devices

that are subtle, or applications which are embedded into a mainstream device such as a mobile phone, can help individuals feel less stigmatised or 'labelled'.

The following two subsections reflect on research which has been conducted to make mobile phones more accessible to people with vision loss (Section 2.3.1) and research into assistive applications for visually impaired people (Section 2.3.2) which are either delivered via mainstream devices and can be used whilst in motion (e.g., mobile phones), or are embedded within an environment which can be in motion (e.g., public transport), or within which the user can be in motion (e.g., smart homes).

2.3.1 Making Mobile Devices Accessible for People with Low Vision

Mainstream mobile devices are typically visually and physically demanding and are, therefore, not particularly accessible to individuals with visual impairment (Guerreiro *et al.*, 2010). This situation has been further exacerbated by the increasing ubiquity of touchscreen-based mobile devices which rely even more heavily on visual interaction techniques. Interestingly, however, the perceived limitations of the small keypads and screens on mobile devices, as well as their recognised inappropriateness for use within contexts where visual attention has to remain on the physical environment for safety reasons, has led to research into the use of touch and audio to enhance and/or replace traditional reliance on visual display resources for general user groups, not just those with visual impairment. Innovation in these areas has explored use of sensory modalities other than vision – for example, speech recognition (e.g., Griol and Molina, 2015a), non-speech auditory feedback (e.g., Brewster, 2002; Park *et al.*, 2015), haptic (touch-based) feedback (e.g., Brewster *et al.*, 2007), and multimodal input (e.g., Griol and Molina, 2015b) which combines different sensory modalities – to reduce dependence on visual interaction (e.g., Williamson *et al.*, 2013). Recent advances in the likes of vibrotactile, text-to-speech (TTS) and gestural recognition systems have consequently opened up scope for increased accessibility to devices for persons with visual impairment as is illustrated via the examples discussed below.

Human-computer interaction (HCI)-based research is increasingly exploring the possibility of supporting truly 'eyes-free' interaction methods for smartphones and other handheld devices (e.g., Dicke *et al.*, 2010; Wang *et al.*, 2015). Whilst much of this research has been motivated by the need to preserve users' personal safety when in environments which dictate that they cannot devote their visual resource to interacting with the device, the innovations themselves are of obvious benefit to individuals with impaired vision for whom there is no option to devote their visual resource to interacting with a device. *Foogue* (Dicke *et al.*, 2010) is an eyes-free interface that enables users to access and input information into mobile phones by exploiting spatial audio and gestural input. It substitutes the need for visual attention by employing audio- and haptic-based interaction techniques. Specifically, information items (e.g., mp3 files) and software applications (e.g., mp3 players) are represented audibly within the 360° space around the user – that is, sounds representing the various items, including those that are currently playing (such as an mp3 file loaded into an mp3 player), appear to originate from specific locations around the user when listened to via headphones. The user interacts with these audio representations to, for example, point to and select and open files or close a running application via physical arm/hand gestures made whilst holding the mobile device. By adopting the combination of audio and haptic interaction modalities, *Foogue* avoids any requirement at all for visual display and interaction.

Brewster *et al.* (2003) proposed two novel solutions for eyes-free, mobile device use. The first presented information items to users via an audio 3D radial pie menu (positioned around the user's head); to select an item, a user was required to nod his head in the direction of the sound corresponding to the desired item. Brewster *et al.* (2003) instantiated this interaction technique for a current affairs application whereby topic choices for weather, traffic, sport, and news were presented using snippets of identifiable audio – weather noises, traffic noises, the theme tune to the television show "A Question of Sport", and the theme tune to a news channel, respectively – and the user nodded in the direction from which the sound appeared to originate in order to listen to that particular type of information. They also instantiated it for a music player in which musical genre, artists, albums, and tracks were

represented via music snippets in a nested hierarchy which was interacted with in much the same way. Determined to find a more practical way to interact with mobile devices when in motion, Brewster *et al.* also developed a sonically-enhanced 2D gesture recognition system whereby a user could draw large shapes and other characters on a belt-mounted mobile device touchscreen in order to issue commands to the device; the trace of a gesture was accompanied by non-speech audio feedback to inform users as to the progress and accuracy of their gestural input. Although neither of their innovations were specifically designed for visually impaired users, both techniques entirely avoid visual displays and demonstrate scope for sound- and gesture-based interaction techniques that could significantly improve the accessibility of IT devices for the visually impaired.

The rise of mobile technologies that are incorporating touch sensitive screens has resulted in a corresponding increase in research into touchscreen accessibility for the visually impaired. The biggest issue with touchscreen phones (particularly for the visually impaired user population) is a lack of tactile feedback that was traditionally afforded by the physical keys on older models of phones. To overcome this, Neff *et al.* (2010) split the issue of touchscreen accessibility into icon presentation on one half of the screen and effective interaction with the icons on the other half of the screen. They have established a design framework which, like the work described above, is based on the use of spatialised, non-speech sounds to present icons and the implementation of physical gesture movement for interaction with the icons. Whilst Neff *et al.* (2010) have published details of their framework, to date no results of user-studies have yet been published.

The *Slide Rule* (Kane *et al.*, 2008) interface provides several audio-based multi-touch interaction techniques that facilitate access to touchscreen applications for visually impaired users. It overcomes the accessibility barrier of touchscreens by providing a “*talking touch-sensitive*” (Kane *et al.*, 2008, p.73) interface – an interface that is speech-based and has no visual representation. It lays out objects on the screen spatially using linear lists; users navigate through and scan lists of on-screen objects by brushing their fingers down the

device surface, and use gestures to interact directly with on-screen objects they encounter. A set of four multi-touch gestures is used to allow users to interact with on-screen objects: (1) a one-finger scan for browsing lists (e.g., *Slide Rule* speaks the first and last name of each contact in a phone book as a user slides his/her finger over each contact from the top of the screen to the bottom in order to find a particular contact); (2) a second-finger tap for selecting items (e.g., the user holds one finger down over the selected contact, which has already been read aloud (see (1))), and then taps anywhere on the screen with a second finger to select the target beneath the first finger); (3) a multi-directional flick gesture for performing additional actions (e.g., the user flicks to the left for replying to a selected message); and (4) an L-select gesture for browsing hierarchical information (e.g., in a music player application, the user first scans his/her finger down the screen to find the desired artist, then to the right to move through songs by that artist). *Slide Rule* was developed according to a user-centred design methodology. Specifically, formative interviews were conducted with eight visually impaired users to elicit requirements; this was then followed by iterative prototyping of the system with three visually impaired users. This participatory approach to user-centred design meant that direct input from target users shaped the development of a cohesive set of interaction techniques based on key issues raised by potential users. For instance, it was identified that it was very important for users to minimise the need to search for and select on-screen items through trial-and-error; consequently, the second-finger tap gesture, described above, was developed to lessen the accuracy demands when selecting items on screen and activating other options. Subsequent pilot evaluation studies with five visually impaired users have shown that participants enjoyed interacting with the touchscreen and recognised its potential.

AudioBrowser is a similar information access tool for touchscreens which enables users to browse stored information and system commands via a combination of both speech- and non-speech audio feedback (Chen *et al.*, 2006). Users are guided by speech and non-speech audio as they move around the screen which is split into two to allow the user to differentiate the information display from the control display. As users' fingers move across

the screen, non-speech audio is used to inform them when they cross a boundary; within a given segment of the screen, speech-based audio informs the user of the information contained therein. A key advantage of *AudioBrowser* is that it supports a hierarchical structure that enables users to access information (e.g., webpages, personal documents, audio files, etc.) whilst on the move (and unable to look at the screen of their device) by following a direct, logical path.

Kulyukin *et al.* (2011) investigated different approaches adopted by visually impaired users when interacting with touchscreen user interfaces on mobile phones. Participants' feedback highlighted the importance visually impaired users attribute to quality of experience in comparison to task efficiency: despite being the least time-efficient design, touchscreen interfaces based on horizontally-structured hierarchies are generally preferred by users with visual impairment. This is one example of the importance of seeking and using qualitative information from representative end users – ideally via their direct involvement – in the design, development and evaluation of such technologies.

Aside from issues of mobile phone inaccessibility, visual impairment presents general challenges in daily life in terms of interacting with everyday appliances which have IT-based or computerised interfaces. To overcome these challenges, Nicolau *et al.* (2010) have developed a personal mobile controller: this is an assistive application embedded within a mobile phone which is designed to allow users to interact with intelligent environments (environments that consist of computerised technology). The device was designed to meet requirements that were elicited via interviews with visually impaired users to determine the difficulties they experience in use of ubiquitous technologies. The device downloads the appropriate interface specifications for the computerised technology within a given environment and generates a single, consistent, usable interface on a mobile phone which acts as a controlling interface for all computerised devices in the surrounding area, thus making the environment accessible via a single interactive controller for an individual to use.

The personal mobile controller is particularly useful for a user who is entering a new environment where the appliances are unfamiliar – for example, using a microwave in a new workplace. It reduces the embarrassment of having to ask others for assistance or attempting to understand the interface when there are other people around who may need to use the same appliance. Connelly *et al.* (2006) argue that visually impaired users are likely to use mobile technologies since these are deemed as non-stigmatising and are associated with ‘affluence’ and ‘success’. Having the capacity to support control of different interfaces and manifesting this control via a mobile phone as an intermediary device, the personal mobile controller exploits these positive attitudes towards mobile devices and provides a single point of interaction with multiple complex technologies within an environment. Preliminary evaluation of the personal mobile controller revealed that users liked the controller and were able to explore and control computerised devices such as microwaves easily. Nicolau *et al.* (2010) propose to evaluate the personal mobile controller in field trials with members of the target user group.

As mobile technology gains sophistication and widespread use, research is on-going to make mobile phones and other handheld computer devices more efficient, cost-effective, functional and accessible. The examples above represent just some of the work in the field of haptic interaction, spatial audio displays, and gestural recognition that is leading to the emergence of increasingly accessible means by which to interact eyes-free with mobile technologies.

In addition to more generalised innovation in the field of accessibility and usability of mobile devices discussed above, researchers have also explored the prospect of Braille displays as a specific form of haptic (touch-based) interaction for visual impairment. Whilst obviously only useful to visually impaired users who have been trained in the use of Braille, research in this area represents a commitment to making mobile devices more accessible. The simplest of such approaches is *BrailleTap* (Guerreiro *et al.*, 2009). Here, each mobile phone key represents a Braille character which the user can select to represent a letter of the alphabet. Using keys on the keypad as Braille cells allows the user to input text and form messages.

This method has proven useful for visually impaired users. Jayant *et al.* (2010) introduced *V-Braille* which, by conveying Braille through vibration on a touch screen, allows users who are Braille-literate to interact with mobile phone interfaces. The traditional Braille structure is imitated on a mobile interface by dividing the screen into six parts: when the screen is touched within these parts, vibrations of different strengths represent a character which allows users to differentiate between characters. Preliminary evaluation of *V-Braille* based on field studies and post-test semi-structured interviews with nine potential end users showed there is scope for introducing Braille as an alternative and useful presentation paradigm.

MoBraille is a novel framework for facilitating accessibility to many of the features of Android smartphones by connecting the phone to a Braille display which serves as an input/output platform (Azenkot and Fortuna, 2010). Braille displays operate by electronically raising and lowering different combinations of pins to reproduce in Braille what appears visually on a portion of the smartphone screen. *MoBraille* makes it possible for an Android application to interface with a Braille display over a Wi-Fi connection, thereby enabling Braille display users to access applications (including the compass and GPS-based facilities) on their phone. For example, *MoBraille* enables visually impaired users to access real-time bus arrival information by displaying the information on their Braille display via their smartphone: at his current bus stop, a user points his phone towards the street which is identified based on GPS coordinates, he confirms his location via a button press, and enters the route number via his Braille display, after which the Android application displays arrival information which is translated into Braille and presented on the Braille display. *MoBraille* was developed based on sound understanding of end users' needs, wants, and expectations acquired as a result of conducting a series of semi-structured interviews with end users to understand the challenges they face and by engaging them in participatory design activities. As a result of their close focus on the end users during design, some very important findings were discovered and incorporated into the design: for instance, somewhat contrary to designers' initial design conceptions, "*conciseness and training*" were favoured over "*discoverability*" (Azenkot and Fortuna, 2010, p.318) – users preferred an interface requiring training and

memorisation as opposed to the initially proposed interface based on self-explanatory messages. Although the reported *MoBraille* proof-of-concept focussed on access to bus timetable information, it has the scope to be used as a platform for many other types of applications, such as a barcode scanner.

2.3.2 Mobile Device-Based Assistive Technology for People with Low Vision

Established research into handheld device accessibility has demonstrated that users with visual impairment can effectively interact with small keypads and screens where non-visual input and output modalities are used to compensate for the lack of visual display resources (Leonard *et al.*, 2006). On this basis, and with on-going advances in mobile technologies, it is becoming ever more feasible for visually impaired people to rely on mobile handheld devices to capture information necessary for interrogating and understanding their surroundings, and to remotely access large amounts of information which can then be used in a myriad of ways to improve their level of independence, mobility, and quality of life.

Lack of independence and safe mobility, which is itself a barrier for other everyday activities, is ranked as the most significant barrier depriving individuals with visual impairment of a normal everyday living experience (Alzuhair *et al.*, 2014). Highlighting the vital impact mobile assistive technology can have in this capacity, the following subsections of this review introduce innovation in mobile assistive technology according to key assisted-living functions designed to sustain individuals' independence. Specifically, the discussion highlights innovation in navigation and way-finding support, obstacle detection, space perception and independent shopping. It is important to note that some of the aforementioned assisted-living functions are also supported by robotics and within smart homes and, as such, may also appear in subsequent related discussions.

2.3.2.1 Navigation and Way Finding

Undoubtedly, sighted guidance (relying on a person with sight as a guide) is an effective means of mobility assistance for visually impaired pedestrians; it reduces mental demand during travel and, as such, also reduces the level of psychological stress associated with travelling (Garaj *et al.*, 2003). Consequently, researchers have attempted to combine technological solutions with sighted guidance to arrive at teleassistance systems (e.g., Scheggi *et al.*, 2014; Baranski *et al.*, 2010) – a remote guidance concept whereby, based on technologically recorded and transmitted environmental information, remote sighted guiders provide visually impaired users with verbal descriptions of the users' environment as well as directional instructions. Common to all navigational teleassistance systems is the need for the visually impaired pedestrian to carry a backpack containing a digital webcam, GPS receiver, and mobile phone with microphone and earpieces; the navigating pedestrian is guided by spoken instructions from a sighted guider who receives information (typically in the form of video images) about the pedestrian's location on a personal computer via a wireless/3G connection and provides verbal direction over the same infrastructure. Although undoubtedly useful, current teleassistance systems tend to impede individuals' sense of personal independence and privacy. Further research is therefore required into both user acceptance and development of such teleassistance systems to better support visually impaired pedestrians' independent navigation.

In contrast to teleassistance systems, which require the involvement of sighted support operators, more truly independent mobile device-based navigation/way-finding applications are quickly becoming one of the more successful approaches for supporting unsighted mobility. One such example is *Voice Maps* (Stepnowski *et al.*, 2011), a system for point-to-point navigation and independent mobility for visually impaired users in urban areas. It operates on an off-the-shelf, touchscreen smartphone and is designed to support optimal route navigation for individuals with visual impairment. It takes advantage of Android's text-to-speech mechanism for generating voice messages, vibration for screen accessibility, and gesture recognition for text input. An interesting feature of the system is that, besides finding

the optimal route, it continuously monitors a user's direction and relevant position; where a user deviates from the recommended path, it informs the user and suggests alternative or corrective actions. No user evaluations had been carried out at time of writing.

Sánchez and de la Torre (2010) developed a mobile phone-based system which uses a combination of audio input/output and GPS technology to facilitate visually impaired users' mobility in both familiar and unfamiliar environments. Users press a button on their mobile device to sign in. Based on their current GPS-detected location, users can (a) search through different destinations that are read out to them by the text-to-speech (TTS) synthesiser, and (b) hear information regarding the distance and direction required to get from their current location to their selected destination. The TTS provides directions based on a clockwise metaphor structure, whereby the user's current position is always assumed to be facing 12:00 and turning directions are given relative to this orientation. Despite being limited by lack of support for obstacle detection and assistance with crossing streets, user evaluations with visually impaired participants showed that, with practice, the tool can be used to help visually impaired people explore new places.

Mobility and autonomy with respect to public transportation systems is a regularly reported difficulty that visually impaired people face. The RAMPE system has been designed to assist visually impaired pedestrians when travelling by public transport (buses and tramways) (Baudoin *et al.*, 2005). The system is based on Wi-Fi-enabled smart handheld devices carried by the users, fixed base-stations installed at bus stops to communicate with the users' handheld devices via a Wi-Fi connection, and a central system (connected to both the base-stations and buses/tramways) for sending real-time information about public transport to the base-stations. User needs, which underpin the system, were elicited using semi-structured interviews with end users and via direct observations of intermodal urban transit of individuals with visual impairment. The RAMPE application allows the user to decide on the stops he wants to connect to in order to receive relevant directions (including information about the changing environment) during his transit. Once at a given stop, the user can listen

to the list of stops along a line about which he is interested. The application can adapt itself to the type of passenger information system available at the stations and react to real-time information: for example, the static information (e.g., number of stops on a line) can change (e.g., as a result of updating of the database), or an urgent event/change can occur (e.g., accident, unforeseen disturbance, delay) in which case the user is informed immediately of the situation using the TTS synthesis, and must acknowledge the receipt of this urgent message by a button press. In addition to the speech synthesis, it supports a dynamic keyboard depending on the states of the application: a normal mode and an urgent mode. In normal mode, each button has a specific function (e.g., the silence button puts the speech synthesis in pause), whereas in urgent mode (e.g., in the case of the aforementioned example of an urgent change), all the buttons allow the user to acknowledge the receipt of an urgent message. User evaluation conducted in a real urban transport environment with 23 visually impaired participants confirmed the usefulness of the system; the use of the device gave rise to an accurate mental representation of the travel.

A similar mobile assistant has been developed for orienting visually impaired people within a Metrobus environment (Mata *et al.*, 2011). The system consists of a smartphone, GPS, and compass device, all of which communicate via Bluetooth. The system provides an audible interface designed to assist visually impaired users to browse through menus and options by listening to relevant information. The main purpose of the mobile assistant is to locate and orient (based on clockwise directions) the visually impaired user within the Metrobus environment. For instance, the user can find out where the station exit is located by pressing a button key; once the required information is received from the GPS and compass devices, relevant audio files are played to the user; if, for example, the exit is located towards the east, the audio file will say "*The exit is located at three o'clock*". User evaluations conducted in Metrobus stations with twenty visually impaired participants confirmed that the mobile assistant contributes to their overall navigation performance by increasing their confidence and sense of security.

2.3.2.2 Obstacle Detection

The solutions described in the previous section focus exclusively on systems for directing users from point A to point B. Complete solutions for independent and safe navigation for visually impaired individuals also require support for obstacle detection to warn users of the presence of potential obstacles or hazards in their path such that they can be safely avoided.

The long cane is claimed to be the most common and successful mobility aid used by people with visual impairment because it helps users detect obstacles and hazards in front of them whilst moving (Shoval *et al.*, 2003). Although this aid is inexpensive, it impedes detection of static obstacles that are not located on the ground, and necessitates users to actively scan the area ahead and around them (Lee *et al.*, 2014). To overcome these challenges, , researchers have developed IT-based navigation devices that help prevent collision with obstacles and/or caution the user about hazards. The systems reported in this section include systems which focus solely on obstacle detection as well as some that enhance navigational assistance with the added advantage of obstacle detection/avoidance.

SmartVision is a navigation aid which electronically enhances and complements the long cane for guiding users to a particular destination while avoiding obstacles *en route* (Jose *et al.*, 2011). *SmartVision* supports local navigation by path tracking and obstacle detection, and covers the area in front of the user and just beyond the reach of the long cane such that the system can alert users to obstacles ahead of them before their long cane would touch them. For indoor navigation, a combination of Wi-Fi with Geographic Information Systems (GIS) is employed; for outdoor use, GPS is required. As a fail-safe solution (e.g., when GPS is not available due to bad weather) users are assisted by environmentally embedded RFID (Radio Frequency Identification) tags; an RFID reader embedded within the long cane detects such tags in the pavement, and the information from it is then automatically interpreted and used to guide the user. Further, the user is equipped with a stereo camera (that is, a camera with two lenses that stimulates human binocular vision and supports the capture of three-dimensional images) attached at chest height, a portable computer worn in a shoulder-strapped pouch or pocket, an earphone, and a small four-button device for menu

navigation and option selection. An audio interface is used for menu navigation and providing information about points of interest. When obstacles are detected, vibration actuators in the handle of the long cane inform users to change their direction. At time of writing, the prototype is still under development; researchers are actively considering the interplay between helping users avoid obstacles whilst remaining centred on the correct navigational path.

Calder (2010) designed a novel prototype ultrasound system for warning users about obstacles in their path. The system, which has a tactile display, is hands-free and can be used as a substitute for and/or supplement to the long cane. The system supports two modes of operation: a hands-free mode, where a tactile interface (using a system of vibrational actuators or tactors) has been developed to be used on the trunk of the user's body; and an augmentative mode – where tactors are attached to the handle of a modified long cane to be used against the palm of the hand. Vibrations inform users about obstacles across their path. Only where an object is detected suddenly will an audible sound complement the signal from tactors. On the basis of promising results from initial tests with visually impaired participants, more advanced versions are under development to combat issues associated with drop-offs such as steps down or potholes in the road surface.

Zhang *et al.* (2010) have also developed a hands-free device to complement the long cane. Their device incorporates (a) a sensor unit installed underneath and at the front of the user's shoe for detecting road surface reflectance (e.g., black surface marking to indicate the existence of a danger zone ahead) and obstacles respectively, and (b) a small feedback unit worn on the user's arm for providing vibration signals based on the surfaces and obstacles detected by the sensor units. At time of writing, the prototype is under development, with the focus being on the hardware more than the software; user evaluations are planned to ascertain the usefulness of the system once further developed.

Adopting another perspective, researchers at Michigan University developed the *Navbelt* (Shoval *et al.*, 2003) – a belt assembled with ultrasonic sensors to provide auditory feedback to individuals with visual impairment to enable them to avoid obstacles and navigate along a required path. When they detect obstacles, the sensors send a signal to the control unit (a portable computer carried by the user in a backpack) which processes them and converts them into audio output which is relayed to the users via headphones. Specifically, where no obstacles are detected, the audio feedback is of a low, barely audible volume, indicating safe and correct travel direction; where obstacles are detected, the volume of the audio feedback increases in inverse proportion to the distance to the obstacles ahead. Extensive user-based evaluation of *NavBelt* during its 5-year long development process highlighted a drawback in that users were unable to understand and cognitively process the guidance signals at a pace that kept up with their walking speed.

The *GuideCane* (Shaik *et al.*, 2010) was developed to overcome the problems associated with the *NavBelt*. It is an advanced version of the long cane which travels on wheels to support its weight. Built with 10 ultrasonic sensors, it is able to detect obstacles in its path and the wheels are equipped to steer in the direction dictated either by the user (via a joystick or manually), or automatically by the system via an embedded computer. When the *GuideCane* detects an obstacle via its ultrasonic sensors, its embedded computer analyses the environment to find a suitable alternative course for the cane to steer around and then physically guides the user along that course.

While both *GuideCane* and *NavBelt* can identify the user as being visually impaired, a potential drawback with both systems, however, is that both could be considered to be embarrassing to use and to draw attention to users making them potentially more vulnerable and to feel stigmatised. To combat this, alternative, discreet devices are being developed. For example, Peng *et al.* (2010) have proposed a smartphone-based obstacle sensor for the visually impaired. With the smartphone held at a 45° tilt angle, the user walks forward until the phone vibrates to indicate that the path ahead is not safe. Users have two options to

identify a safe alternative path: (1) the system provides verbal instructions to indicate which sides are safe to move to and the user can choose to make directional changes based on this audio feedback; and (2) the user can point the phone in other directions until the vibration stops, signifying that it is safe to proceed in the selected direction. Although an evaluation of this system returned positive results overall, users did find it difficult to hold the phone at the requested tilt angle at all times. Further limiting the usefulness of the system is its constrained means of mapping the terrain ahead, coupled with an underlying assumption that there will always be a small region in front of the user that is safe (i.e., no dead ends) and overlooking potential safety issues of walking around with a phone in front of users on display.

With the aim of guiding individuals and helping them avoid obstacles, Amemiya and Sugiyama (2009) proposed the *haptic direction indicator* – a small, handheld mobile device based on the ‘pseudo attraction-force technique’. The method generates the force sensation by exploiting human-perception characteristics; their prototype of a handheld force feedback device with asymmetric acceleration (accelerated more rapidly in one direction than in the other) allows the holder to experience the kinesthetic illusion of being pushed or pulled continuously when holding the device and thus indicating the appropriate direction in which to travel. If the user takes a wrong turn, the system changes the direction of the force vector to encourage the user to return to the predefined route. One of the key strengths of this system (and others that use haptic force sensations) is that it prevents the over use of audio feedback; since visually impaired users rely on their sense of hearing to gain information regarding their environment it is important not to occlude or interrupt that with too many audio stimuli. User evaluation with twenty three visually impaired participants confirmed the usefulness of the system; participants were able to recover the intended original route by employing the force feedback and proved that the proposed system can be used to provide navigation directions via kinesthetic sensation without any previous training (Amemiya and Sugiyama, 2010).

Intelligent glasses are a non-invasive travel aid to provide navigation to visually impaired people (Velázquez *et al.*, 2003). Cameras mounted on users' eyeglasses frames can be used to detect obstacles in their environment and translate this information into haptic feedback which is presented via a tactile display carried by the user. Users can carry this tactile display, which has similarities to a map, whilst they are walking and interact with it via their sense of touch (much like some of the previously discussed systems) to determine their position, path and any obstacles they might encounter.

2.3.2.3 Space Perception

"A navigation system should not only lead a navigator, but it should also be able to deal with the dynamic environments that they navigating regardless of familiarity" (Quinones *et al.*, 2011, p.1649). Safe navigation through and presence within one's environment involves not only knowing the appropriate path to take from point A to point B (see Section 2.3.2.1) and being able to detect and avoid obstacles along that path (see Section 2.3.2.2), but also being able to perceive, interpret, and comprehend one's surrounding physical space (Strumillo, 2012). This section considers systems that have been designed to help visually impaired users with the last of these tasks.

Cognitive mapping is of crucial importance for individuals in terms of creating a conceptual model of the space around them and thereby supporting their interaction with the physical environment (Jacquet *et al.*, 2006). The *Haptic Sight* study was designed to provide immediate spatial information to visually impaired users, enabling them to walk through an environment while being more aware of their surroundings (Song and Yang, 2010). Using direct observational and interview-based knowledge elicitation methods, researchers initially tried to gain an understanding of a visually impaired person's indoor walking behaviour and the information required to walk independently. They found that to walk successfully independently, visually impaired people need to be aware of their current location, the direction they are heading, the direction they need to head for, and path information to the destination. Only once the research team had established a depth of understanding in this regard did they develop a handheld device-based application. The *Haptic Sight* interface

wirelessly receives environmental information via ultrasonic and/or infrared sensors which it translates into a tactile presentation of building layout information using raised blocks on a touch surface. As such, when holding *Haptic Sight*, users are able to sense their surroundings via touch. At time of writing, this research is still in its early stages and researchers continue to work closely with visually impaired users to verify and refine the concept.

Timbremap (Su *et al.*, 2010) is a mapping application for off-the-shelf touchscreen mobile devices. It uses audio feedback to guide a user's finger along the lines of a digitally-rendered geographical map in order to allow users to develop a cognitive understanding of geometrical (representing geographical) information, and thereby to contextualise their surroundings (which will, in turn, allow them to deal with unforeseen circumstances). The *Timbremap* interface provides output feedback using two non-speech sonification (audio) modes to convey or perceptualise data. The first mode is the line hinting mode: this guides users' touch along path segments and, if a user's finger drifts off a path segment, a variety of audio feedback is used to indicate to the user how to return to the path to continue tracing it with his/her finger. The second mode is the area hinting mode: this informs the user about the number of paths around the edges of the screen, about gaps between path segments, and about the existence of any intersections in paths. Users can pan the map by positioning their primary finger on any spot on the map, then holding any of the four corners of the screen with a secondary finger and dragging the primary finger to pan the map in the direction of the secondary finger. To listen to points of interest (POI) markers on the map, the user holds one finger on the POI marker and double taps anywhere on the screen with a secondary finger. The concept of *Timbremap* is very much in line with the findings of recent research (Bradley and Dunlop, 2005) which highlighted the significance of understanding the cognitive maps that visually impaired people form to navigate in unfamiliar environments (i.e, what spatial information do visually impaired people rely on) and the benefit such understanding can bring to the development of navigational aids for people with vision impairment who are at immense disadvantage in unfamiliar environments, as they lack much of the information

required for navigating and avoiding hazards and obstacles this research highlights the importance of collaboration between the disciplines of human-computer interaction (which encompasses psychology) and clinical science to investigate the formulation of cognitive maps by people with different visual impairments for the purpose of developing context-aware navigation services for visually impaired people.

MobileEye aims to help visually impaired users to see and understand their surroundings during independent travel and other activities via the use of a phone's camera and text-to-speech (TTS) technology (Liu *et al.*, 2010). The system consists of four subsystems adapted for different types of visual disabilities: (a) a colour channel mapper to help the user distinguish colours around them; (b) a software-based magnifier for providing image magnification and enhancement to facilitate reading and understanding of objects; (c) a pattern recogniser for recognising certain objects such as money; and (d) a document retriever for allowing access to printed materials by using only a snapshot of a page and retrieving the document from a large document database. Every operation of the software is guided by a voice message. The user activates the camera by two key presses to prevent accidental activation, and the software automatically exits after being idle for two minutes. The researchers acknowledge that further research is required to enhance the *MobileEye* concept (e.g., improved response time and evaluation of the TTS and vibrational feedback) and note that, from a computer science perspective, a major challenge for designers is "*reaching the end user*".

Shen *et al.* (2008) have developed a similar mobile phone-based system which uses the phone's inbuilt camera to help the visually impaired find crosswalks and, more importantly, cross them safely. With this system, when users approach a crosswalk, they take an image of the crosswalk which is then analysed by software run on the phone; the results of this analysis are conveyed to the users via audio feedback/instructions to assist them in crossing the crosswalk safely. The latest version of the system detects two-stripe crosswalks (these crosswalk patterns consist of two narrow white stripes bordering the crosswalk, and are

much more challenging to detect due to the small number of features) in real time and helps users to stay inside the crosswalk boundaries when crossing (blind users report difficulty in maintaining direction when crossing a road due to the lack of immediate ambient features (Bradley and Dunlop, 2005)). Future work will reportedly focus on further user interface development, more sophisticated functionality and further user testing.

Researchers have investigated the concept of using smartphones for exploring points of interest in new places. *LocalEyes* is a GPS-based application with a configurable multimodal interface which has been designed for Android smartphones to facilitate visually impaired users' navigation and awareness of the environment around them (Behmer and Knox, 2010). It allows them to explore information about, for example, surrounding points of interest including restaurants, coffee shops, etc. Users can establish their current location and orientation by simply tapping the screen and then accessing information about local points of interest by using simple gestures (e.g., scroll-up, scroll-down). Currently, information is communicated to users via speech (which can be switched off when required) as well as on screen via large, high contrast text. A Braille output display and a version of *LocalEyes* for the iPhone are reportedly being developed and user-studies are planned to evaluate the system once these are in place.

2.3.2.4 Independent Shopping

Independent and safe mobility is vital for independent shopping. Visually impaired people have ranked shopping centres as one of the most challenging environments through which to navigate, and the overall shopping experience as a challenge (Lamoureux *et al.*, 2004). The complexity of shopping as an activity for people with visual impairment has been recognised in innovation within mobile assistive technologies.

Researchers at Utah State University offer a comprehensive analysis of design requirements for such solutions and identify the main activities underpinning conventional shopping behaviour as (a) product selection and browsing before purchasing, (b) navigating within a store, and (c) searching for and identifying actual products (Kulyukin and Kutiyawala,

2010a). On the basis of their analysis, they developed *ShopTalk* (Nicholson *et al.*, 2009) – a system to assist visually impaired shoppers to navigate through a store and locate target products by scanning barcodes both on shelves and on individual products. *ShopTalk* consists of a set of headphones (for verbal route instructions), a barcode scanner (assembled with stabilisers designed to rest on shelves to make it easier for users to align the scanner with the barcodes), a numeric keypad and a computational unit. *ShopTalk* guides the user in the store by issuing route instructions in two modes: location unaware mode (LUM) and location aware mode (LAM). LUM verbal route directions are generated based on (a) a ‘topological map’ built into *ShopTalk* at installation time by walking through the store, noting decision points of interest (e.g., store entrance, aisle entrances, cashier lane entrances), and then representing them in the map, and (b) a database of parameterised route directions based on the ‘topological map’. Such guidance relies on the shopper’s orientation and mobility skills, as the system itself is unaware of the shopper’s actual location and orientation. The LUM mode can only be activated by pressing the Enter key. Conversely, LAM mode issues location-aware instructions and is activated by a barcode scan (a barcode scan also switches the mode from LUM to LAM); a barcode scan informs the system about the shopper’s exact location and helps the user navigate amongst the aisles. This approach relies on a barcode connectivity matrix, where product information (e.g., aisle, aisle side, shelf, section, position, description) is in-built from the store’s inventory database. Studies of *ShopTalk* have shown a high success rate for product retrieval; the identified limitations to the system were the requirement to carry a set of hardware components and the need for the system to be able to access a store’s inventory control. In recognition of these limitations, an improved version has been developed – *ShopMobile-2* (Kulyukin and Kutiyawala, 2010b) which is delivered on a mobile platform and utilises the smartphone’s camera as barcode reader. Although user studies have been conducted, no results have as yet, at time of writing, been published.

A further smartphone application for grocery shopping (specifically, for searching for and identifying products) – *BlADE* – has been developed by Tekin *et al.* (2013); when the user

scans an item's barcode, it is checked for a product match in the database and the results are read out to the user. User studies with visually impaired participants demonstrated the feasibility of the application, and suggested the real-time feedback (to help the user find barcodes before they are read) as a key advantage to improving its usability.

BlindShopping is another similar smartphone-based system with the added advantage of guiding users through a store; in this case, users have to carry a long cane and, based on information sensed via an RFID (Radio Frequency Identification) reader attached to the tip of the long cane and RFID tags distributed throughout the aisles of the supermarket, verbal navigation instructions are provided via a headphone connected to the smartphone (López-de-Ipiña *et al.*, 2011). Once at the target product section, the user can point the camera phone to QR (Quick Response) or UPC (Universal Product Code) codes attached to the shelf section beneath the product, to receive verbal information about that product.

2.3.2.5 Smart Homes and Robotics

Designed to safeguard users' wellbeing in their own homes, robotics and smart homes (that is, homes embedded with assistive technologies) now offer individuals opportunities for independent living, often with added benefits in the form of facilities to reduce social isolation. Although smart homes themselves are stationary, a person living within one of these homes is mobile whilst using the embedded technology around them. Furthermore, development of smart homes assists users' mobility and other life activities associated with independent living. Mobile robotics is a more recent area of research in the assistive technology field. In this review, discussion of smart homes and robotics overlaps since the field of robotics generally incorporates the traditional concept of a robot, along with components of robotics that are used in mobility aids and smart homes.

The primary concept of a smart home is to offer independent living and provide a safe environment for individuals with disabilities, including visual impairment (e.g., Forlizzi *et al.*, 2004). The INHOME project (Vergados, 2010), which supports a number of specifically-targeted user requirements based on data from relevant literature and on feedback from

health-care professionals (e.g., nursing/medical staff, social workers), is designed to assist people in private residences with the aim of providing a higher degree of independence and safe living in their home environment. INHOME monitors individuals within their homes and enables remote control and configuration of home appliances; it provides error and status messages (concerning the safety of their home) via an INHOME terminal or a TV set. For instance, while watching TV, a user may wish to receive, delivered to the TV set, status information about another home appliance (e.g., washing machine) as well as being able to remotely control and configure the operation of the washing machine. When the washing machine cycle has finished, for example, an alert message can be displayed on the TV screen accompanied by an audio alert. Likewise, the user can be informed if, after switching on a cooker, he/she has forgotten to place a pan over the heat; for safety, if the user does not react to the alert within a specified time interval, the cooker can be switched off and interested parties (agreed and decided on by the user) might be notified. Together this monitoring and level of remote control helps individuals feel safe in their own home. Furthermore, the INHOME mobile terminal incorporates parallel use of speech recognition and a touch screen to receive commands from users to ensure that they can maximise their feeling of control.

Virtual house calls are now possible through interactive IT-based technology. Deegan *et al.* (2008) explored the concept of a robotic mobile manipulator which helps an individual with a variety of manual tasks. Part of the ASSIST project, a multi-institutional and interdisciplinary research project, the mobile manipulator was being developed based on sound understanding of users' special needs, lifestyles, preferences, residential geometry and environment. Notably, focus groups revealed that elderly people with impairment are more likely to accept and use technological solutions if they understand the consequent benefits (e.g., independent lifestyle, improved safety). Utilising a network of camera sensors, the mobile manipulator comprises a mobile interface to facilitate remote communication with the outside world (e.g., a family member), a microphone, and a speech synthesiser. The camera sensors continuously monitor areas where movement is most likely to occur to detect any

abnormalities (e.g., objects on the way, evidence of fall). As discussed in Section 2.3.2.2, obstacle detection is very important for visually impaired people and an individual's home is no exception: trip hazards can arise when objects are moved out of their normal location or when objects accidentally drop to the floor. The likelihood of accidents (e.g., falls) as a result of such hazards can be eliminated by detecting and removing them. For example, a box left in a hallway by a delivery person can be detected and located by the mobile manipulator using the camera sensors; the mobile manipulator is then guided autonomously using these cameras towards the object. Once the mobile manipulator determines that it is in contact with the object, it attempts to move it out of the way by applying force to the object. Not only does the mobile manipulator help individuals with manual tasks, but it can increase their safety by immediately contacting family members or emergency medical care in the case of an accident.

Furthermore, robotic systems are also emerging as technological means for combating mobility issues. A novel robotic system has been designed to assist visually impaired people with navigation, obstacle detection and space perception (Capi and Toda, 2011). The system consists of a camera, laser range finders and a small PC placed on a trolley walker (i.e., a 4-wheeled trolley with two handles and a tray attached to the bottom to house the PC) equipped with sensors. Significantly, it has the capacity to detect hazards like stairs and steps – an important requirement established via interview-based studies with the visually impaired. Additionally, the robot can distinguish between human and inanimate objects in the users' path based on the camera image: when obstacles are detected, users are cautioned via beep signals or via natural language, e.g., "*be careful on the right*" or "*stairs, stairs*". Future work will reportedly involve increasing the number of sensors on the walker, using a rotating camera for detecting moving objects, and including a GPS system for outdoor environments.

Although research has shown that mobile robots can now be used in healthcare (especially in eldercare) (Krishnan and Pugazhenth, 2014), in smart homes, in therapy to assist

individuals with manual tasks, to help decrease loneliness or to act as a virtual interface to provide remote monitoring and communication (Hersh and Johnson, 2012), their use typically raises ethical issues concerning individuals' sense of freedom, dignity, and their human rights (e.g., Perry and Beyer, 2012).

2.3.3 Summary

The above review illustrates the wide-ranging research and innovation in the field of mobile assistive technologies that has been aimed at assisting visually impaired individuals to lead a more independent life and the crucial role such technologies can play in substituting for a lost capability. Mobile phones and other mobile technologies can facilitate portable solutions that support users in an unobtrusive, ubiquitous capacity aided significantly by the fact that they are discrete and non-stigmatising.

Despite the increasing number of laudable and exciting innovations in the field of mobile assistive technology for the visually impaired, only in a minority of cases has a user-centred design philosophy been comprehensively adopted. There is some, but relatively limited, evidence of the use of individual elements of UCD, including participatory design, focus groups, and, most commonly, interview-based studies and user evaluation studies. Where such methods have been adopted, they have demonstrated the extent to which they can assist designers in making informed choices in developing devices based on users' needs, wants and expectations. In particular, MoBraille is a clear case where functionalities preferred by users overpowered designers' initial design concepts. Furthermore, there is little evidence of the direct involvement of clinicians (or domain experts) in what has been substantively research owned by the computer science domain. The field of human-computer interaction has long been advocating the involvement of stakeholders in software development processes in recognition of the higher levels of user acceptance returned when such approaches are adopted. The notion of stakeholders extends to include not just end users but also domain experts and other individuals who play a significant role in the contextual make-up of the end users. In the case of technology for individuals with visual impairment, stakeholders range from the individuals themselves (who should be considered the experts in living and coping with their impairment), family members and carers, as well as

clinicians. Obviously, engaging individuals with disabilities in an empowered way can present logistical difficulties; advice from and involvement of domain experts such as clinicians is essential to overcome these challenges and thereby fully empower the individuals to participate in the development process. It is only when the range of stakeholders is engaged with the process that the software designers and developers can be sure that they are not overlooking functionality and interactivity that is deemed essential by the user group.

2.4 Assistive Technology for Older Adults with AMD

Notwithstanding the significant contribution of the above surveyed innovations which highlighted the spectrum of innovation in this field, and thereby the scope for improving the independence and quality of life for individuals with visual impairment, designing IT for people with age-related macular degeneration (AMD) is a relatively under-researched area; furthermore, individuals with AMD have not traditionally been directly involved in the design of technology to support their needs and abilities, despite its potential to have a positive impact on their quality of life (Brody *et al.*, 2012). Significantly, initial attempts to analyse and recognise the impact of AMD on older adults' use of computers have only emerged since the turn of the century. For example, when comparing iconic visual search strategies for computer users with normal vision and users with AMD Jacko *et al.* (2001) found, perhaps unsurprisingly, that users with normal vision consistently outperformed users with AMD. The issue has subsequently been further investigated in terms of the impact of graphical user interface screen features on computer task performance in users with AMD (Scott *et al.*, 2002a; Scott *et al.*, 2002b). Results from these studies concluded that visual function parameters and clinical features (e.g., visual acuity, contrast sensitivity, and colour vision defects) are substantively associated with computer task accuracy; in particular, icon size was found to be significantly associated with computer task accuracy, whereas background colour was not found to be a significant predictor of task accuracy.

Studies have also examined the effect of multimodal feedback on the performance of older adults with AMD when performing drag-and-drop direct manipulation tasks. Comparison of the performance of drag-and-drop tasks by older adults with different visual abilities (29 older adults with normal vision and 30 adults with AMD) observed improvement in performance across all participants when multimodal feedback (e.g., combination of visual, auditory and haptic feedback) was provided (Jacko *et al.*, 2003). While haptic feedback alone did not improve participants' performance, when combined with auditory feedback it resulted in improved performance. It is also important to note that participants with more severe AMD benefited from tri-modal feedback and, in particular from feedback with an auditory component. These findings are reiterated in the results of a subsequent study by Jacko *et al.* (2004); examining the effects of multimodal feedback on the performance of older adults with AMD, the authors confirmed that visual feedback alone leads to poor performance, whereas auditory feedback, combined with other forms of feedback, supports an improved performance for older adults with AMD.

Attempts have also been made to devise recommendations and guidelines for making user interfaces more accessible for users with AMD. Based on their study comparing the visual search strategies of older adults with AMD to those of normal sighted participants, Jacko *et al.* (2002) proposed the following two guidelines for making user interfaces more accessible to users with AMD:

- **Guideline 1:** *“Use a blue, black, or white background colour instead of green or red background colour as an additional accessibility feature for users with AMD.”*; and
- **Guideline 2:** *“Use an icon size of at least 2.6 degrees of visual angle for users with AMD (an icon larger than about 2.6 degrees of visual angle does not necessarily lead to an increase in performance).”*

Additionally, they recommended that researchers consider the following when designing user interfaces for older adults with AMD:

- use of larger graphical images with high-contrast displays;
- careful organisation and amount of information on screen;

- present only important and relevant information;
- icon size is of crucial importance; and
- position of graphical elements is important.

One of the first studies into handheld graphical user interface (GUI)-based computer interaction for older adults with AMD was conducted by Leonard, Jacko, and Pizzimenti (Leonard *et al.*, 2006; 2005), who identified that severity of the disease, design efforts and strategies, and contrast sensitivity were important indicators for successful iconic search using, and manipulation of, handheld computers by this user group. Beyond this, however, research into designing technology to match the abilities of this user group to date has been limited to a more general focus on desktop computers for visually impaired users rather than (mobile) assistive technologies for persons with AMD despite their potential advantages. A recent study comparing digital e-readers and standard print media for people with AMD, for instance, suggested that such devices – with larger display screens and high contrast ratios – could have potential benefits for older adults with AMD when used in visual rehabilitation (Gill *et al.*, 2013).

2.5 Design Approaches to Assistive Technologies

As previously noted, the global population of people aged 60 years and older is growing rapidly. Suggested healthcare reforms reflect the need for a future model of healthcare delivery wherein patients take more responsibility for their own healthcare in their own homes in an attempt to moderate healthcare costs without impairing healthcare quality (Institute of Medicine, 2008; Nobel and Norman, 2003; Anderson and Horvath, 2004). Healthcare technology designed for patient use has the potential to empower patients to become increasingly engaged in improving their own health and taking on a more active role in their healthcare (Wolpin and Stewart, 2011; Demiris *et al.*, 2008); assistive healthcare technologies have the potential to enable users to live more independently, to improve users' quality of life, and to better sustain their healthcare. For such a paradigm shift to be realised, the supporting healthcare technology must address the needs of older patients efficiently and

effectively to ensure technology acceptance and use (Anderson and Horvath, 2004; Carol et al., 2002).

A large number of healthcare-related information systems currently fail to achieve expected success due to lack of sufficient involvement of stakeholders during the design process (Teixeira *et al.*, 2012): users are expected to adapt to technological solutions which were intended to increase efficiency, productivity, etc. but which stand little chance of doing so given the processes by which they were developed (Zhang, 2005). In order to fully realise the benefits of such technologies, the technologies must meet patients' real needs and capabilities effectively and this is best achieved via direct stakeholder involvement throughout the technology design and development process as advocated by approaches such as universal/inclusive design and user-centred design (UCD) discussed below.

2.5.1 Accessibility and Universal Design

In recent years, many research activities have focused on designing systems that are usable by anyone across a range of abilities using any technology platform. This means designing for diversity – accommodating users with various impairments (i.e., sensory, cognitive and physical), of different ages, and from diverse cultures and backgrounds (Vilar, 2010). Approaches such as universal and inclusive design encourage designs that address the above issues and better consider the needs of atypical users such as the elderly and the disabled (Keates *et al.*, 2002; Obrenovic *et al.*, 2007). It is widely accepted that universal *design*, or design for all (both terms often used interchangeably), is primarily concerned with designing systems that address the needs of all potential users (Obrenovic *et al.*, 2007) or at least that aim to ensure an equivalent experience for all users (Dix, 2010); in contrast, universal *accessibility* is traditionally associated with the notion of designing for users with special needs (Stephanidis *et al.*, 1998). Nevertheless, the underlying philosophy of both concepts is to ensure designers do not exclude users as a result of their design choices. Table 2.1 lists the 7 Principles of Universal Design; not all 7 principles are equally applicable in all situations, but rather they are intended to encourage designers to appropriately

consider the requirements for designing for special needs users such as the elderly and the disabled.

Table 2-1: 7 Principles of Universal Design [<http://universaldesign.ie/What-is-Universal-Design/The-7-Principles/>]

| |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Principle 1: Equitable Use <i>The design is useful to people with a range of abilities and appealing to all.</i> Guidelines:</p> <ul style="list-style-type: none"> a) Provide the same means of use for all users: identical whenever possible; equivalent when not. b) Avoid segregating or stigmatizing any users. c) Provisions for privacy, security, and safety should be equally available to all users. d) Make the design appealing to all users. |
| <p>Principle 2: Flexibility in Use <i>Design allows for a range in ability and preference.</i> Guidelines:</p> <ul style="list-style-type: none"> a) Provide choice in methods of use. b) Accommodate right- or left-handed access and use. c) Facilitate the user's accuracy and precision. d) Provide adaptability to the user's pace. |
| <p>Principle 3: Simple & Intuitive to Use <i>Regardless of the knowledge, experience, language, or level of concentration of the user.</i> Guidelines:</p> <ul style="list-style-type: none"> a) Eliminate unnecessary complexity. b) Be consistent with user expectations and intuition. c) Accommodate a wide range of literacy and language skills. d) Arrange information consistent with its importance. e) Provide effective prompting and feedback during and after task completion. |
| <p>Principle 4: Perceptible Information <i>Design should provide effective communication of info regardless of environmental conditions or users' abilities.</i> Guidelines:</p> <ul style="list-style-type: none"> a) Use different modes (pictorial, verbal, tactile) for redundant presentation of essential information. b) Provide adequate contrast between essential information and its surroundings. c) Maximize "legibility" of essential information. d) Differentiate elements in ways that can be described (i.e., make it easy to give instructions or directions). e) Provide compatibility with a variety of techniques or devices used by people with sensory limitations. |
| <p>Principle 5: Tolerance for Error <i>Minimising impact and damage caused by mistakes or unintended behaviour.</i> Guidelines:</p> <ul style="list-style-type: none"> a) Arrange elements to minimize hazards and errors: most used elements, most accessible; hazardous elements eliminated, isolated, or shielded. b) Provide warnings of hazards and errors. c) Provide fail safe features. d) Discourage unconscious action in tasks that require vigilance. |
| <p>Principle 6: Low Physical Effort » <i>Systems should be designed to be comfortable to use, minimising physical effort and fatigue.</i> Guidelines:</p> <ul style="list-style-type: none"> a) Allow user to maintain a neutral body position. b) Use reasonable operating forces. c) Minimize repetitive actions. d) Minimize sustained physical effort. |
| <p>Principle 7: Size & Space for Approach & Use <i>Placement of system should be such that it can be reached and used by any user regardless of body size, posture, or mobility.</i> Guidelines:</p> <ul style="list-style-type: none"> a) Provide a clear line of sight to important elements for any seated or standing user. b) Make reach to all components comfortable for any seated or standing user. c) Accommodate variations in hand and grip size. |

It has been argued that designing for specific atypical users might sometimes render the resulting technology harder to use for users without impairments, or perhaps impossible to use for people with other impairments (Newell and Gregor, 2002). In contrast, Wobbrock *et al.* (2011) advocate the philosophy of ability-based design, which encourages designers to refocus from users' disabilities to their abilities – that is, to focus on what users can do rather than work around what they can't. They have derived 7 principles (see Table 2.2) to support the application of this thinking; these focus on the designers' stance (i.e., their focus on users' abilities), the interface (in terms of its adaptability and transparency), and the system (measuring performance, context and commodity).

Table 2-2: 7 Principles of Ability-Based Design (Wobbrock *et al.*, 2011, p.11).

| | | | |
|------------------|--------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------|
| STANCE | 1. Ability. | Designers will focus on ability not dis-ability, striving to leverage all that users can do. | <i>Required</i> |
| | 2. Accountability. | Designers will respond to poor performance by changing systems, not users, leaving users as they are. | <i>Required</i> |
| INTERFACE | 3. Adaptation. | Interfaces may be self-adaptive or user-adaptable to provide the best possible match to users' abilities. | <i>Recommended</i> |
| | 4. Transparency. | Interfaces may give users awareness of adaptations and the means to inspect, override, discard, revert, store, retrieve, preview, and test those adaptations. | <i>Recommended</i> |
| SYSTEM | 5. Performance. | Systems may regard users' performance, and may monitor, | <i>Recommended</i> |
| | 6. Context. | Systems may proactively sense context and anticipate its effects on users' abilities. | <i>Recommended</i> |
| | 7. Commodity. | Systems may comprise low-cost, inexpensive, readily available commodity hardware and software. | <i>Encouraged</i> |

HCI-based research has also long been exploring the use of multimodal interaction techniques to improve accessibility for users with diverse needs and abilities; the principle is to design systems that integrate various human perceptual channels (e.g., sound, touch, taste, and smell) and, as such, do not rely only on the visual channel as the primary presentation method (and so disadvantage users with visual impairments) (Obrenovic *et al.*, 2007; Turk, 2014). This proposed utilisation of natural human senses could, in addition to

increasing bandwidth of interaction between humans and their technological environment, support the principle of redundancy in universal design (see Table 2.1) (Story, 1998); this principles states that the same information should be delivered using different channels, thus empowering users to rely on their non-impaired channels (McGee-Lennon *et al.*, 2012). Focusing on the abilities of the visually impaired (e.g., sense of touch, auditory capacity, remaining vision), for example, has led to advances in technology specifically for this user group, including but not limited to: interactive maps using tactile and auditory output (Brock, 2013); a novel exergame, Eyes-Free Yoga, using auditory feedback based on skeletal tracking (Rector, 2014); a computer-based drawing system that integrates their haptic and/or sensory channels in addition to the visual one (Headley and Pawluk, 2010); a system to teach and learn handwriting via haptic and audio output/feedback (Plimmer *et al.*, 2008); and a study examining the use of haptic and audio information for displaying shapes (Crossan and Brewster, 2008).

Despite such advances, a recent review into multimodal interaction identified the need for enhanced frameworks for design and evaluation of such systems (Turk, 2014). This is largely because multimodal systems, similar to the aforementioned arguments for universal accessibility, should be designed for users with different abilities and needs, as well as different context of use (Reeves *et al.*, 2004).

A recent review which analysed 30 years of ageing research in the domain of HCI found very little research is, in fact, exploring the heterogeneity of older adults to account for their specific (age-related) differences and needs (Vines *et al.*, 2015b). Moreover, there is a noticeable lack of representative sampling of older adults in HCI research in general (Sears and Hanson, 2012) and so more needs to be done to encourage direct user involvement in the design, development and evaluation of any technological solution for older adults with AMD; this is likely best achieved via User-Centred Design (UCD) approaches, as discussed below.

2.5.2 User-Centred Design (UCD)

UCD is a philosophical approach to technology design which places the user at the centre of the design process. The involvement of stakeholders in software development processes has long been advocated in recognition of the proven higher levels of user acceptance of the resulting technology (e.g., De Rouck *et al.*, 2008). UCD encourages the use of a range of user-focused design tools and practices including interviews, focus groups, surveys, usability testing, and participatory design (PD) processes (e.g., Cober *et al.*, 2012). PD is the ultimate UCD method whereby end users (and domain experts) are included as equal participants in the design team as opposed to only being consulted using the other methods mentioned (further discussed in section 2.5.3). Findings suggest that the use of UCD tools is critical to success in any technology development, but this is especially true when entering and developing for a niche market, such as assistive technologies for the visually impaired. UCD also gives vulnerable individuals a direct mechanism by which to convey their concerns with regard to what they see as negative aspects of technology designs which, if unvoiced, could result in the target user group's failure to accept the technology (i.e., could lead to total abandonment of technology).

The notion of stakeholders extends to include not just end users but also domain experts and other individuals who play a significant role in the contextual make-up of the end users. In the case of technology for individuals with visual impairment, stakeholders range from the individuals themselves (who should be considered the experts in living and coping with their impairment), family members and carers, as well as clinicians. Obviously, engaging individuals with disabilities in an empowered way can present logistical difficulties (Connelly *et al.*, 2006); advice from and involvement of domain experts such as clinicians is essential to overcome these challenges and thereby fully empower the individuals to participate in the development process.

Pragmatically, it is recognised that the inclusion of individuals with disabilities and domain experts in the design process is not without its challenges (Crabtree *et al.*, 2003; Dewsbury

et al., 2003). Prior research in the field of mobile assistive technology development has led to guidelines for effective inclusion of special needs users in the design process. Based on practical work with special needs users, Leung and Lumsden (2008) recommend the following general guidelines for successfully involving target users (and domain experts) in the design and evaluation of assistive mobile technology for special needs users:

(1) "*Work with Existing Support Organisations*": working with organisations that support individuals with the particular disability under consideration is an effective means of overcoming any difficulties with involving target users in the design process and as a natural vehicle for including domain experts;

(2) "*Assess Target Users' and Domain Experts' Needs, Abilities, and Expectations*": gaining a good understanding of both the users' and domain experts' personal characteristics and their expectations regarding the design project can minimise the likelihood of problems arising due to mismatched expectations and thus result in successful collaboration;

(3) "*Choose a Design/Evaluation Technique and Analyse its Requirements*": the prior guideline can help researchers to decide on appropriate design/evaluation techniques/tools, and analyse the demands they place on the user;

(4) "*Adapt the Chosen Approach to be Sympathetic to the Target Users' Abilities*": chosen design techniques need to be refined based on lessons learned from initial attempts to use them so that they are fully adapted to the users' needs and expectations;

(5) "*Clearly Communicate the Nature of Participants' Involvement*": it is essential to clearly communicate to target users and domain experts the exact nature of their involvement, and the design project's goals, so that any mismatched expectations that have the potential to harm the project can be avoided;

(6) "*Attempt and Refine the Approach*": once a technique has been deployed and its effectiveness evaluated, it is essential to refine and improve it based on the lessons learned from practice; and

(7) "*Evaluate the Technology in Different Contexts*": controlled evaluations (e.g., in a laboratory) can be valuable for initial usability assessments, but to gain a better

understanding of technology's long term usability and effectiveness, it should be evaluated with target users in many contexts (e.g., at home, outdoors) .

Focusing specifically on the inclusion of domain experts (Allen *et al.*, 2007), and based on their own experience, Allen *et al.* (2008) offer an introduction into the involvement of domain experts when designing assistive technology and provide the following general guidelines for such involvement:

- (1) "*Anticipate the necessary domain experts' roles and match the available experts to the roles*". Allen *et al.* suggest determining the different roles domain experts can play in the design project (e.g., additional researchers, liaison between the research team and the users, representatives of the target user), and then carefully matching the available domain experts to the required roles;
- (2) "*Recognise the lack of expertise in a particular domain related to the design or target user*". It is important to recognise any missing skill set early so that its impact on the project is anticipated and it can be compensated for;
- (3) "*Anticipate and mitigate possible interference between roles when a domain expert plays multiple roles*". It is advantageous to consider possible scope for interference when a domain expert assumes multiple roles, anticipate problems, and suggest possible solutions;
- (4) "*Consider domain experts' interest in research, perspectives, and expectations*". It can be problematic if the domain experts' expectations and motivations are either not considered or are not in harmony with the project goals;
- (5) "*Clearly communicate roles and research goals to involved domain experts*". Clear communication between the domain experts and researchers can ensure that all members understand their expected involvement and how they are expected to contribute towards the research goals.

On-going investigation is needed to expand on these early collective guidelines and, in particular, to devise a set of guidelines specifically for the design and development of mobile assistive technology for the visually impaired.

To understand the extent to which stakeholders, and in particular end users, have participated to date in the design and development specifically of patient-centred healthcare-related technologies (as opposed to more general assistive technologies discussed in Section 2.3), a further, dedicated review of the literature catalogued in PubMed was conducted. The search was limited to focus on research studies that reported healthcare technology for patients' use only, and had the design/development of technology rather than its implementation as the primary topic. The aim was to discover the extent to which UCD methods/tools are being applied in the design and development of technology-based healthcare interventions for patients' use. Only articles that described the development of a healthcare-related application, device or system for patients where the application required user interaction, were included in this review. As such, articles that focused on the back-end of the technology (e.g., Li *et al.*, 2008) or required limited input from/interaction with users (e.g., Vervloet *et al.*, 2011) were excluded from this review. In total, 18 articles were reviewed in detail (see Table 2.3).

Table 2-3: Participatory research/UCD methods reported by all 18 papers reviewed.

| Summary of the reviewed technology showing UCD methods adopted. | | UCD Tools Applied | | | | | | |
|--------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------|-------------------|------------|----------------------------|--------------------------|---------|-------------------------|-------------------|
| Healthcare Technology | Description | Focus Groups | Interviews | Surveys/ Questionnaires | Observational Studies | Diaries | Participatory Design | Usability Testing |
| Personal Health Application (PHA) for diabetes (Fonda <i>et al.</i> , 2010) | The prototype PHA receives data on major self-management domains, analyses, and provides simple feedback. | ✓ | | | | | | ✓ |
| Mobilehealth monitoring system (Suh <i>et al.</i> , 2012) | A remote monitoring system for monitoring health status of patients with diabetes. | | | | | | | ✓ |
| Heart rate monitoring system (Segerstahl, 2009; Segerstahl and Oinas-Kukkonen, 2011) | Heart rate monitoring systems employing a wearable heart rate monitor and web service. | | ✓ | | | ✓ | | |
| Mobile phone technology for asthma (Ryan <i>et al.</i> , 2005) | A system employing a handheld electronic peak flow meter connected to a mobile phone. | | | | | | | |
| Cardiac rehabilitation | Provides supervised cardiac | | | | | | | ✓ |

| | | | | | | |
|----------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------|---|---|---|---|---|
| monitoring system (Worringham <i>et al.</i> , 2011) | rehabilitation to patients via a smartphone, ECG and GPS based system. | | | | | |
| RemoteLogCam (Güldenpfennig and Fitzpatrick, 2013) | A wearable device to help an individual with cerebral palsy to self-manage hand spasms. | ✓ | | | | ✓ |
| Self-Management of pulmonary rehabilitation (Marshall <i>et al.</i> , 2008) | Uses a smartphone to train users to undertake exercise. | ✓ | | | | |
| Personalised diabetes telecare (Tsai <i>et al.</i> , 2012) | Provides personalized diabetes healthcare services for patients on smart phones | | ✓ | | | ✓ |
| Mobile tool to support lifestyle changes (Jürgensen, 2011) | A tool to help people to take action against obesity and stay motivated for making and maintaining a lifestyle change | | | | ✓ | |
| HealthAware (Gao <i>et al.</i> , 2009) | A real time system to prevent obesity by enhancing individual daily healthy behaviour | | | | | ✓ |
| Telehomecare for patients with multiple chronic illnesses (Liddy <i>et al.</i> , 2008) | A telehomecare unit collects patient data on vital signs and health information from patients to be accessed by care providers | ✓ | ✓ | ✓ | | |
| Active Lifestyle (Silveira <i>et al.</i> , 2012) | An IT-based system for active and healthy ageing aiming at improving elderly's balance and strength | | | ✓ | | ✓ |
| VIVOCA (Hawley <i>et al.</i> , 2013) | A voice-input and voice-output communication aid people with severe speech impairments | ✓ | ✓ | ✓ | | ✓ |
| Us'em (Markopoulos <i>et al.</i> , 2011) | A device for motivating stroke patients to use their impaired arm-hand in daily life activities | ✓ | ✓ | | | ✓ |
| AUBADE (Katsis <i>et al.</i> , 2006) | Recognizes emotion and allows the user to view the facial animation generated from the estimated emotion state. | | | | | ✓ |
| HealthGear (Oliver and Flores-Mangas, 2006) | The system monitors the subject's SpO2 and pulse while sleeping and automatically detects sleep apnea events | | | ✓ | | ✓ |
| HealthWeaver Mobile phone application (Klasnja <i>et al.</i> , 2010) | Supports cancer patients' unanchored health information management with mobile technology | ✓ | | ✓ | ✓ | ✓ |
| Interactive robotic device (Tiwari <i>et al.</i> , 2011) | A device empowering older patients to engage in self-care (e.g., medication management) | ✓ | | ✓ | ✓ | ✓ |

Both this review (as well as the more extensive survey of assistive technologies reported already) largely reinforce anecdotal observations that the practical application of UCD research approaches for the purpose of software design is rarely comprehensively documented (or even discussed) in detail within the interdisciplinary HCI community. Of the 18 papers reviewed, 1 paper (6%) reported no use of UCD methods/tools at all, 6 papers (33%) reported the adoption of only 1 method, 6 papers (33%) reported adopting 2 methods, 2 papers (11%) reported use of 3 methods, and 3 papers (17%) reported adopting 4 methods; no project reported using more than 4 of the listed methods, with a maximum of

just over half of the available methods being used in any one project. The most commonly adopted method was user testing, followed by interviews, with project teams apparently favouring the less structured methods but more easily set up methods overall (Vredenburg et al., 2002; Gunther et al., 2013). It is important to note that the frequency of usage of a method does not necessarily reflect its usefulness; methods that are typically ranked highly for practical value can be infrequently used due to cost-benefit trade-offs when selecting UCD methods or, as previously noted, due to the lack of knowledge about different UCD methods.

Whilst it is encouraging that user-focused evaluation is being conducted, this is far from a truly UCD-based approach to *design* in that the users are only being engaged when there is something to test, rather than being democratically included as an integral part of the design process itself. UCD-methods were used in 8 of the 18 projects for knowledge elicitation, and it is here that researchers often engaged more than one UCD method (e.g., focus groups, interviews, observational studies, etc.). Only 4 of the 18 projects utilised UCD methods during the design phase of their research; this is perhaps the most critical phase in which to engage users in order to return a design which is likely to garner user acceptance, with the relative absence of the use specifically of participatory design methods (further discussed in Section 2.5.3) being especially noteworthy in terms of the degree to which users were being engaged in this part of the process.

Together with, and in particular in terms of the general lack of design-stage utilisation of UCD methods, this review corroborates previous findings which indicated that UCD is generally under-utilised in the area of healthcare technology innovation (Searl *et al.*, 2010); furthermore, where user participation is reported, the experience is not well documented.

Although we reviewed the extent to which participatory or UCD methods are utilised in the healthcare domain specifically, it should be noted that this under-utilisation of such methods is likely a gross underestimation in terms of its impact on technology use by people with

health-related needs because the review hasn't included publications where the focus has been on development of technology for disabilities rather than healthcare; as our review of assistive technologies in Section 2.3 demonstrated, the situation is no better in the latter. Nevertheless, studies in the field of healthcare technology innovation that are advocating the practical use of UCD or participatory HCI when developing patient-centred healthcare technology (e.g., Searl *et al.*, 2010) indicate that such undertaking does not need to be a costly or challenging undertaking – for example, it can focus on working with target users on paper-based mock-ups and/or conducting interviews (Wolpin and Stewart, 2011).

One criticism of much of the literature on UCD is that its *proven* benefits are not widely enough reported to successfully realise the full benefits of engaging older adults (with impairments) in the design and development of novel technologies (this review failed to disclose studies directly comparing take-up of technology designed by adopting UCD process with those not designed in this way, for instance). Some of the evidence reported in this chapter, however, hopefully demonstrates how when older adults (with impairments) are empowered through being given a voice in design, technologies/devices emerge that can, for instance, support individuals with dementia reclaim the ability to perform an activity they used to be able to carry out prior to the onset of dementia (Wherton and Monk, 2008); or support older adults to lead more healthier lifestyles by “improving their understanding of how to eat healthfully and engage in nutrition-related analytical thinking”, “reevaluate the healthiness of their real life habits”, “form helping relationships by discussing nutrition with others” and “start replacing unhealthy meals with more nutritious foods” (Grimes *et al.*, 2010). Difficulties arise, however, when an attempt is made to measure (or to prove) effectiveness of the benefits of UCD. Kohno *et al.* (2013), for instance, propose a pragmatic approach to analysing the cost benefits of UCD (e.g., by comparing development time and cost for current UCD projects with past projects not using UCD). When analysing the effectiveness of UCD approach for 22 projects of a company, the following positive outcomes were observed: (1) there was an increase in sales volume and profits as a results of understanding problems of the target users' perspectives; (2) some reported reduced cost in product development; and (3) others

suggested improved quality of product and operational efficiency (Kohno *et al.*, 2013). Overall, what this review has demonstrated, is that adopting UCD approaches for the design and development of assistive technologies can help researchers/developers to form an enhanced understanding about target users' needs and preferences, and, as a result, make well reasoned design decisions from the user's point of view (Kujala and Väänänen-Vainio-Mattila, 2009). It is hoped that research presented in this dissertation provides additional evidence with respect to the benefits of UCD approaches, by contributing to an enhanced understanding of how and why UCD methods should be applied when working with special needs users such as older adults (with AMD) when designing technology to meet their needs.

2.5.3 Participatory Design Approaches

PD or participatory research, as applied to technology development, refers to a democratic approach to technology design that calls for end-user involvement in the design process, and in which end users are actively established and empowered as co-designers in the process.

PD originated in Scandinavia in the late 1970s, driven by Marxist commitment to both encourage democracy in the workplace and democratically empower and encourage its employees to advise on new technologies to be introduced into the workplace (Ehn and Kyng, 1987; Ehn, 2008; Spinuzzi, 2005; Floyd, 1993).

Researchers in the field of HCI adopting the participatory design philosophy recognise that they are not simply designing for themselves (to their own preferences) or for people with similar abilities and needs, but are instead designing for individuals who are often very different in terms of needs, capabilities, and attitudes (Cheverst *et al.*, 2003). In their recent review of how people are involved in design and participate in research within HCI, Vines *et al.* (2013b) consider three main goals motivating and underpinning such participation: sharing control; sharing expertise; and inspiring change, contributing to the growing body of evidence that older adults (with impairments) can be effective co-designers of technological solutions to meet their needs and abilities (e.g., Lindsay *et al.*, 2012a; Lindsay *et al.*, 2012b;

Vines *et al.*, 2012b; Lumsden *et al.*, 2005; Davidson and Jensen, 2013a; Williamson *et al.*, 2013; Massimi *et al.*, 2007; Massimi and Baecker, 2006; Lumsden *et al.*, 2010)

While it could be argued that conventional participatory methods are not always entirely appropriate when designing for a large diversity of users (Stojmenova *et al.*, 2012), or could result in disagreements stemming from conflict of interest arising as result of the inclusion of multiple voices of interest (Reymen *et al.*, 2005), or are challenging to apply when engaging individuals with impairments (Connelly *et al.*, 2006), it is nevertheless imperative that users' needs, capabilities and wants are given extensive attention when designing technologies for their use. To this end, selected PD methods can be modified and adapted to participants' capabilities – as illustrated by our own practice reported in Chapter 5.

There is also a track record of researchers within HCI who increasingly involve target users in the design and development of technologies by adopting PD approaches. For instance, Wu *et al.* (2005) adopted PD methods to design and develop an orientation aid – Orienting Tool – for amnesics to assist them when they feel lost or disoriented by providing information regarding their whereabouts and intentions. Their experiences (including outcome of the project) demonstrated that PD is a viable approach for involving special needs users with cognitive impairments in the design of technology. Similarly promising results have been noted by Moffatt *et al.* (2004) who used PD methods to design a daily planner for people with aphasia, by Lindsay *et al.* (2012a) who used PD methods to design a “safe walking aid” for older adults with dementia, and by Vines *et al.* (2012a) who collaborated with older adults aged 80 years and over to design digital payment services. Likewise, Massimi *et al.* (2007) used participatory activities with older adults to transform an off-the-shelf mobile phone into a specially-designed memory aid and Lumsden *et al.* (2010) engaged in participatory activities with functionally illiterate adults to design and develop a mobile application to support their language learning. Their experiences, which are consistent with those already mentioned, confirm the potential benefits of engaging older adults (with impairments) in the design and development of technology to support their specific needs.

It isn't only older adults (with impairments) who have the potential to benefit from healthcare-related technology designed using PD approaches. For instance, it has been proposed as a 'candidate method' for the design and development of e-Health applications targeted at young women in an attempt to encourage positive health-based behavioural change based on their specific needs and preferences (Duffett-Leger and Lumsden, 2010). Further, Davidson and Jensen (2013b) proposed adapting PD approaches for the design of health-related applications focused on users' needs and wants. Likewise, a recent review into PD approaches for commercial product development acknowledged that such participation could help users to "*visualise*", "*understand*", and "*comprehend*" the potential of new technologies and, as such, increase the adoption of such technologies (Wilkinson and De Angeli, 2014).

While the potential benefits of engaging older adults (with impairments) in the design and development of technology are widely acknowledged, researchers are calling for a more systematic understanding of the challenges and methodological concessions necessary when engaging with older adults, and general understanding of how such participation is planned and managed (Lindsay *et al.*, 2012b; Vines *et al.*, 2013b). Results from a 'Participation and HCI' invited Special Interest Group (SIG) meeting held at the CHI 2012 conference suggest that, while the notion of participatory design is underpinned by the desire to design and deploy technology, it is also about building trust and social equality with participants and their communities; it is about giving users the voice and opportunity to question the decisions often made on their behalf, and to inform the design of novel technologies (Vines *et al.*, 2013a).

Komninou *et al.* (2014) also identified physiological, psychological, cognitive and societal factors (see Table 2.4) that researchers need to consider when selecting design methods with older adults. It is important to note that all the identified factors merely require careful adaptation of the PD approach to target users' needs and abilities as further discussed in Section 5.8.1.

| Factor Category | Issues |
|----------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Physiological | Age factors that make self-reporting inaccurate Limited endurance Medical conditions that hinder motor skills, hearing or verbal expression |
| Psychological | Tendency of blaming themselves instead of designers for issues Fragility of confidence while using technology Anxiety towards computer use Perception that computers are not much use to them Difficulty in focusing on the design process if they feel that it is going towards a direction that is not valuable to them |
| Cognitive | Lack of understanding of technical language and metaphors Lack of underlying understanding of computer concepts Difficulty in envisaging new technology Disapproval of deep explorations in subjects that are forced on them by the designer Tendency to diverge into unrelated subjects during discussions |
| Societal | Participatory design meetings are seen as social events Positive predisposition towards prototypes and tendency to praise rather than offend researchers by offering objective views |

Table 2.4: *Factors that influence the use of design methods with older adults.*

Attempts have been made to devise a set of recommendations or considerations for conducting PD sessions with older adults (with impairments). Massimi *et al.* (2007), for instance, suggest the following recommendations stemming from their experience of conducting PD activities with older adults to design mobile phones: (a) provide alternative activities to ensure everyone in the team can participate fully; (b) create temporary subgroups to overcome deficits; (c) minimise crosstalk; (d) make participation an institutional affair; (e) provide an activity structure; (f) speed up or down to suit the group; and (g) blend individual and group sessions. Lindsay *et al.* (2012b) identified the following four challenges researchers need to consider when engaging older adults in PD activities based on their experience of working with older adults: (a) maintaining focus and structure in meetings; (b) representing and acting on issues; (c) envisioning intangible concepts; and (d), designing for non-tasks. Finally, based on their experience of conducting PD activities for the design of a health-related application, Davidson and Jensen (2013a) propose the following considerations: (a) keep design sessions short; (b) allow for informal socialising; (c) encourage participation; and (d) balance researcher and participant input. Work reported in this thesis echoes many of the aforementioned recommendations and considerations: some have been extended and enhanced to support the researcher's engagement and collaboration with older adults with AMD (as reported in Chapters 4-5).

Despite the aforementioned advancements in the field and attempts to encourage and support a more prevalent adaptation of PD activities within the multidisciplinary community of HCI, challenges still remain as evidence suggests that this approach is not being adopted, or at least reported, widely enough to successfully realise the full benefits of engaging older adults (with impairments) in the design and development of novel technologies. It is further suggested that researchers focus on the design rather than the PD process itself (Vines *et al.*, 2013a). Furthermore, very rarely are participants' gains from PD projects (i.e., how did taking part in a PD exercise benefit participants?), and the underlying reasons and benefits of adopting PD approach fully articulated in the literature.

A recent study examining PD research practice reported in the last 10 years identifies 5 fundamental aspects of PD that require “*reformulation*” (Halskov and Hansen, 2015, p.89). These are: politics (concerned with the reasoning for user participation and the extent to which participants can influence the project); people (since users in PD are also domain experts, researchers should consider carefully whom to involve in the project); context (consideration of what characterises use case situations as an important starting point for the process); methods (consideration of what and how methods are adopted to allow participants to influence the process); and product (what are the outcomes of the PD?). They call for a thorough investigation of the relationship among the above aspects and more longitudinal studies of PD processes (Halskov and Hansen, 2015).

Additionally, there are other fundamental issues that need to be addressed by the multidisciplinary HCI community to support a far more widespread adoption of PD approaches: there are calls for (a) more longitudinal studies on assistive technology design and development that include older adults from the design to deployment and use of such technologies (Davidson and Jensen, 2013b); (b) greater clarity on how user participation occurs under diverse methods of interaction and engagement; (c) investigation into who else benefits from such engagement and how; (d) investigation into how and to what degree control is shared between researcher(s) and participants engaged in PD activities (Vines *et*

al., 2013c); (e) a far more comprehensive and systematic reflection and analysis of how participatory research is conducted and, more importantly, communicated (Simonsen, 2013); and finally, (f) investigation into how participatory research is initiated, managed and, more importantly, “*how do we end participatory research?*” (Vines *et al.*, 2015a; Taylor *et al.*, 2013). For older adults with various (dis)abilities, an additional consideration that should be incorporated into the PD research framework includes their attitudes towards both technology and their own disability, as such attitudes could often influence their willingness to participate in PD activities and, thereafter, technology acceptance and sustained use over time (Hwang, 2012).

2.6 Older Adults’ Attitudes toward Technology

Besides the complex comorbidities from which older adults (with visual impairments) often suffer, there are also specific emotional and behavioural changes associated with their particular condition (or ageing in general) that may influence users’ acceptance of and motivation to use an assistive technology (Hawthorn, 2000). Additionally, degenerative conditions such as AMD will increasingly negatively impact users’ ability to interact with technology over time (as ascertained by research conducted for this thesis). Understanding and relating to these needs is often difficult for researchers and developers with technical (e.g., IT) backgrounds, who typically have limited knowledge about, and experience with, the disability; such understanding and empathy is, however, imperative to appreciate the implications of the target users’ specific capabilities, and to appropriately design to meet those needs.

Traditionally, researchers have subscribed to the belief that older adults may feel sceptical about the need to use or benefits derived from using computers (Saunders, 2004; Festervand *et al.*, 1994), too old to learn to use computers (Turner *et al.*, 2007; Birdi *et al.*, 1997), and have questioned the impact of computer use on older adults’ well-being (Dickinson and Gregor, 2006). The generalisability of misconceptions that older adults are not willing to or capable of learning to use technology is rather problematic, particularly since recent evidence suggests that there has been a growth in the number of older adults using

computer devices. The number of older adults aged 65 years and over (it is estimated 1 in every 10 people over 65 years and over have some degree of AMD) using smartphones in 2014 increased to 20% compared to only 12% in 2012, and more than 40% of older adults now use various devices to go online compared to only about 30% in 2012 (Ofcom, 2014).

Contrary to popular belief, a recent study examining the experiences and attitudes of older adults towards technology has found that older adults are highly motivated to learn (or continue to learn) to use technology, but consideration of their lifestyles and the role of proposed technology is crucial to the successful design of such technology (Caprani *et al.*, 2012). Another study challenging some of the dominant stereotypes associated with older adults' use of and, more importantly, attitudes toward technology, recognised older adults' positive attitudes toward technology use, and suggested their perceived advantages of technology use includes "*supporting activities*" (e.g., health monitoring), "*adding convenience*" (e.g., when technology reduces effort), and "*having useful features*" (e.g., enlarged UI components) (Mitzner *et al.*, 2010).

In their recent comprehensive review of theoretical frameworks for the adoption of technology for older adults, Barnard *et al.* (2013) identify two fundamental components of the use (or abandonment) of technology by this user group: (1) the intention to use technology as underpinned by users' attitudes and perceptions; and (2) the usability of technology in terms of its design.

Theoretical models of intention, attitude, and behaviour have been vigorously studied in recent years by several researchers: one of the earliest studies considering older adults' attitudes toward technology was conducted by Weisman (1983), who reported on older adults' positive attitudes toward computer games as a means for empowerment and improving self-esteem. Another technology acceptance model was formulated by Venkatesh *et al.* (2003) – The Unified Theory of Acceptance and Use of Technology (UTAUT) – which studies users' intentions to use technology and their subsequent usage behaviour. The

theory identifies the following 4 key elements that might impact intention and behaviour: (1) performance expectancy – relates to users' perception of how the technology could help them achieve their desired task; (2) effort expectancy – refers to users' effort required to use technology; (3) social influence – relates to users' awareness about other people's views on using technology; and (4) facilitating conditions – the prospect of displaying actual behaviour (Barnard *et al.*, 2013). UTAUT is grounded upon several models (e.g., Technology Acceptance Model (Davis *et al.*, 1989) and Theory of Reasoned Action (Sheppard *et al.*, 1988)), but predominantly on the Theory of Planned Behaviour (Ajzen, 1991).

Focusing specifically on older adults' acceptance and use of technology, Renaud and Van Biljon (2008) developed the Senior Technology Acceptance and Adoption Model (STAM), which also incorporates users' experiences of using a technology in addition to their perception of ease of use. According to STAM, users initially form an intention to use technology based on social influence and perceived usefulness (similar to the UTAUT model) – this is referred to as the *objectification phase*. Then, users start experimenting with technology – the *incorporation phase* – and, if successful, this will lead to actual use – the *acceptance phase*.

The underlying principle of the model discussed above (and other similar models) is that behaviour is dependent on attitude (Fazio, 1990). Although this suggests that users with more positive attitudes are more likely to use technology, it is also recognised that attitudes are attained and later changed through experience (Petty *et al.*, 1997; Ajzen and Madden, 1986), thus suggesting that positive exposure to technology (from actual use or observing others using technology successfully) can, in turn, positively impact and change attitudes (Jay and Willis, 1992). Consequently, to improve older adults' attitudes and, as such, to motivate them to use technology, it is imperative to better inform older adults about potential benefits of using technology which, in turn, could help to address their computer self-efficacy and anxiety (Melenhorst *et al.*, 2006; Mitzner *et al.*, 2010; Mynatt *et al.*, 2004). For researchers involved (or interested) in designing and developing technology for older adults it

is therefore imperative to understand how older adults perceive and use technology and to effectively engage with this user group to motivate and stimulate positive attitudes toward technology use, which is best achieved by adopting UCD (and PD) research approaches (Holzinger *et al.*, 2007).

2.7 Summary

This section reviewed the research and innovation in the field of mobile assistive technologies that has been aimed at assisting older adults with visual impairments to lead a more independent life and the crucial role such technologies can play in substituting for a lost capability. Mobile phones and other mobile technologies can facilitate portable solutions that support users in an unobtrusive, ubiquitous capacity aided significantly by the fact that they are discrete and nonstigmatising. Despite their immense potential, studies discussed in this section have shown that individuals will only use assistive products which serve their specific needs/capabilities and meet with their acceptance; and, on this basis, it is essential that these individual capabilities are recognised, understood, and accommodated during innovation and design processes in order to deliver assistive technologies that will ultimately meet with user acceptance.

Furthermore, the review suggests that, far from older adults being technologically averse as is often the misconception, their lack of technological acceptance is often rooted in the fact that current devices are not designed with niche special needs or older adults in mind. It also indicated that there is considerable scope for positive impact of technology within this user group if designed based on their needs and wants.

Despite the significant potential for mobile assistive technology to enhance visually-impaired people's healthcare and independent living, persons with AMD have not traditionally been directly involved in the design of technology to support their needs; when designing for a special needs or niche user group such as users with AMD, it is imperative that participatory methods are employed because it is otherwise largely impossible for designers to adequately

understand user needs, to appreciate the implications of their specific capabilities, and to appropriately design to meet those needs, in an attempt to encourage technology use and acceptance.

A methodological limitation of many reported studies to date is that they do not elucidate their design process clearly, failing to identify whether UCD or PD processes have been followed, thereby rendering their methods opaque and failing to provide support and guidance to the design community at large. As such, there are calls for future studies to clearly report on their design methods involving end users.

This dissertation attempts to at least start answering these calls. It details how UCD and PD research approaches were successfully adopted and adapted (where needed) to design, develop and evaluate an assistive diet diary application for older adults with AMD. It demonstrates how appropriate engagement with the user community and adaptation (where needed) of UCD methods can overcome initial challenges involved in building the relationships necessary to engender AMD participants' trust and encourage their involvement in research projects of this nature. A series of older adult-focused enhancements and extensions to existing guidelines for the inclusive design of special needs users are extracted via in-depth reflection on the practices adopted in this research.

Chapter 3. Knowledge Elicitation: Understanding IT-Related Attitudes and Needs of Older Adults with AMD

3.1 Introduction

“Every blind or visually impaired person [...] has different and specific [...] capabilities that need to be supplemented in various ways” (Strumillo, 2010, pg. 24). It is essential that these individual capabilities are recognised, understood, and accommodated during innovation and design processes in order to deliver assistive technologies that will ultimately meet with user acceptance and support people in changing their behaviour. Lack of consideration of user opinion during the design process and changes in their needs are amongst one of the most important factors leading to technology abandonment across the board, and especially in the field of mobile assistive technology where user needs are that bit more specialised (Phillips and Zhao, 1993; O’Rourke *et al.*, 2014). User comments such as *“Listen to me! I know what works for me”* (Phillips and Zhao, 1993, p.42) reinforce the importance of involving target users throughout the design and development of assistive technology.

We firmly believed that a user-centred design approach was the way forward for providing our participants with a direct mechanism by which to convey their concerns with regard to what they see as necessary and/or undesirable aspects of technology designs that, if unvoiced, could result in our target user group's failure to accept the technology (Cheverst *et al.*, 2003).

One of the limitations of current literature relating to technology design for older adults (with impairments) is that whenever UCD methods (e.g., focus groups and observational studies) are applied, their methodological pertinence and appropriateness (including necessary adaptations and modifications) are not sufficiently evaluated and/or discussed.

To this end, it was imperative to work closely with our target user group (i.e., older adults with the specific disability of AMD) to: fully understand the way in which the disease impacts their lives (including over time); develop a full and deep appreciation of what living life from their perspective is like in order to transfer that understanding into our application design; understand their coping strategies for the purpose of determining the research context and setting; and to appreciate how the degenerative nature of the disease might be accommodated by intelligent technology. Without engaging such users in our research, we would never have been in a position to fully understand their requirements and preferences for technology design because we could not claim first-hand knowledge of, and would not propose to accurately imagine, their specific context. It was, therefore, the natural – if not only – choice to adopt UCD methods (and subsequently participatory design as discussed in Chapter 4) in order for our research to include target users and stakeholders (e.g., persons with AMD, clinicians, carers, etc.) throughout all stages from the design to deployment of the proposed diet diary application, in an attempt to maximise the accessibility of the application for people with AMD, and older adults in general.

Addressing the potential benefits and challenges involved in democratically including users – in particular, users from a special needs population – in the design and development of

technological interventions, this chapter reports on our knowledge elicitation activities (e.g., interviews, focus groups and in-home observational studies), highlighting the methods used and their adaptation to support such user participation. It reflects on how user participation was planned and managed for the knowledge elicitation stage of the project in order to appreciate the impact that technology may have on users as well as to inform the design and structure of the proposed technical solution: in particular, this chapter reports on how the participatory research was initiated (i.e., how issues such as establishing relationships with communities/participants and determining the research context were addressed), how focus groups and in-home observational studies were used to collect qualitative ethnographic data about the needs and views of our participants, and discuss how the process to manage ongoing participation and user engagement (for subsequent stages of the project) was, generally, reflected upon, to better understand the practice. Ethical clearance was sought from the Aston University Research Ethics Committee (REC) to conduct our knowledge elicitation activities (including the participatory design activities reported in Chapter 4) (see Appendix A.1).

It is hoped that the research discussed in this chapter further endorses the potential benefit of UCD approaches, and contributes to an enhanced understanding of how and why UCD methods should be applied when working with special needs users such as older adults with AMD when designing technology to meet their needs.

3.2 Phase 1: Establishing Contact with AMD Community and Clinical Experts

The process of establishing contact with the local AMD community and, subsequently, inviting older adults with AMD to participate in our research started by consulting clinical experts (e.g., optometrists, ophthalmologists) from several health organisations (including Solihull Hospital and Focus Low Vision Clinic in Birmingham) in order to attain an overview of AMD and the risk mitigation associated with dietary choices, to potentially elicit their expert opinion on how assistive technology could best fit into the lives of individuals with AMD and,

most importantly, on how to engage individuals with AMD directly in the project. While the researcher had access to Aston University's Ophthalmic Research Group and has closely collaborated with one of their most experienced clinical researchers, this was more a familiarisation phase deemed essential for gaining other clinical experts' professional opinions on our proposed research approach and resulting assistive technology design.

During the initial stages of the project the researcher attended meetings with 5 ophthalmologists and optometrists to attain their expert opinion on our proposed solution (i.e., the diet diary application). At the beginning of each meeting, the researcher provided a brief summary of the project and an explanation of the proposed diet diary application (including its functionality); handwritten notes were taken and later transcribed and analysed (analysis consisted of clustering transcribed data into 'main' themes/groups): the main information/suggestions emerging from these interviews included:

1. the importance of making the effect/outcome of our proposed solution 'perfectly clear' to patients/participants to mitigate against misunderstandings as a result of mismatched expectations;
2. the need for taking into account any vitamins/supplements patients might take and/or possibility of other age-related impairment;
3. information about the effect nutrition can have on different levels of visual impairments; and
4. that 'simplicity' and 'speech input/output' would be key for successful use of our proposed device or any assistive technology in general.

It was anticipated that there would be existing frameworks for involving AMD users in research projects, but we learned, in discussion with clinical experts, that the notion of user participation in the field of ophthalmology was very different from the democratised approach we were proposing. As such, the researcher established direct contacts with the managers of the two local (Shirley and Knowles regions) community support groups for people with AMD. After discussing the project to get a thorough sense of its aims and objectives, both

managers were happy to cooperate and invited the researcher to attend their support group meetings.

The support groups, run by people with AMD for people with AMD, were regular monthly meetings of between 10 – 20 older adults with AMD (and occasionally their caregivers) and provided a valuable opportunity for us to immerse ourselves within the community and start getting to know its members. Over a period of 2 months, the researcher attended 4 meetings (2 meetings per support group) where she had the opportunity to informally introduce herself and the team and the project goals, and to start to learn from the support network and its members about our target users' condition and, accordingly, capabilities and limitations; individuals' concerns, such as the aims and length of the project, the members' involvement and what the project could offer that would be of benefit to members were discussed. At the start of each meeting, the researcher was invited to give an informal presentation (10 – 15 minutes long) about the research project aims and objectives before staying for the remainder of the meeting to enable interested individuals to ask further questions. Interested participants were additionally handed out information about the study and consent forms (in large print) to enable them to discuss, with their families, their participation. They were informed that the researcher would give them a call back in few days' time to confirm their willingness to take part in the study.

This process allowed the researcher to build a trusted professional relationship with individuals with AMD in an environment in which they were comfortable and to ultimately elicit their voluntary involvement in our research.

From consulting clinical experts and attending the local community support group meetings it was apparent that the main reason people expressed for being reluctant to participate in research studies was a misconception that laboratory-based research essentially 'used' people as experimental subjects rather than experts living with their condition. We quickly realised that, in order to fully benefit from their participation in our research, we would need

to address such misconceptions about involvement in our research studies; it was important to convince our participants, in both discussion and action, that they were considered as experts in living with their condition and that our research was entirely aimed at meeting their needs (rather than the other way around). Our success in doing this ultimately led to us being able to invite a subset of the support group participants to take part in the subsequent stages of our project, thus substantially easing the process of finding and recruiting participants for those stages.

3.3 Phase 2: Focus Groups

Focus groups are amongst one of the most widely adopted UCD methods in HCI and can, potentially, be used in any phase (from knowledge elicitation to deployment and evaluation) of UCD-based projects (Lazar *et al.*, 2010). The advantages of adopting focus groups as a knowledge elicitation tool include, but are not limited to, the fact that (a) they allow researchers to gain insight into target users' attitudes, needs, feelings, views, experiences and feedbacks (Gibbs, 1997), (b) the interaction and co-questioning between participants can generate new ideas and stimulate discussion (Lindsay *et al.*, 2012a), (c) this, in turn, can motivate the group to continuously refine information generated (Brondani *et al.*, 2008), (d) they can encourage a great variety of communication from participants, in particular open conversations about more '*embarrassing*' topics (Kitzinger, 1994). Despite these advantages, however, special considerations for engaging older adults, and in particular those with special needs, in focus groups for the design of technology are scarcely documented in the literature (Barrett and Kirk, 2000).

There is, however, some evidence of positive use of focus groups for technology development for older adults (Inglis *et al.*, 2003). Researchers have engaged with older adults to elicit information about mainstream (e.g., Eisma *et al.*, 2004) and 'smart home' (e.g., Demirir *et al.*, 2004) technologies, or have worked with older adults with dementia (e.g., Lindsay *et al.*, 2012a) to deliver condition-specific technologies. Previous research has shown that successful group engagement and interactions stemming from focus groups can

also be carried over into subsequent phases of a development project (e.g., Barrett and Kirk, 2000; Lindsay *et al.*, 2012a), thus eliminating the time and resources required to establish contact with and recruit new participants for follow-up studies (where applicable).

In their comprehensive review of various knowledge elicitation tools for more diverse users (e.g., older adults with impairments), Antona *et al.* (2009) argue that focus groups are one of the very few knowledge elicitation methods that can be used without adaptation when engaging users with visual impairments, but require marginal adaptations and modifications when involving older adults (this is likely due to the adverse impact of other age-related impairments from which older adults might also suffer).

Besides recognising the aforementioned advantages of adopting focus groups for knowledge elicitation purposes in technology design and development, our motivation to use focus groups included several domain-specific reasons. Firstly, during the community support group meetings it was recognised that participants were a little reluctant to talk about their difficulties (in terms of living with AMD) when engaged in one-to-one discussions with the researcher, but were willing to divulge their challenges and daily struggles when other individuals with AMD were involved in the discussion. To this end, it was anticipated that the group dynamic during focus groups would enable participants to feel comfortable in disclosing and discussing common issues. Furthermore, it was observed that a subset of potential participants were openly optimistic about our proposed technological solution and enthusiastic about the prospect of participating in this research study. Thus, it was anticipated their interaction with participants who were slightly more sceptical about the proposed study would engender their positivity and enthusiastic attitude and outlook to all concerned. Finally, it was hoped the group discussions would allow us to fully explore the diversity and unique needs and opinions of older adults with AMD and, by reflecting upon each other's ideas, the findings and learnings from the process would be interconnected and substantiated. The aims and objectives of individual focus groups as well as the study design, process, findings and limitations are discussed in the following subsections.

3.3.1 Study Design and Participants

From the community support groups, 10 volunteers (nine people with AMD and one carer with very early AMD) were recruited for a series of focus groups which ran every few weeks at a venue convenient to the participants – this was generally at the same venue as their normal support group meeting or a nearby coffee shop to remove barriers to participation and put participants at ease. While no financial or gift incentives were provided, all participants were offered refreshments upon arrival to foster an open relationship and engage in social conversation before starting the focus group discussion itself.

Two groups were established (where the individuals within each group knew each other via their respective support group), one which met three times and one which met four times over a period of 4 months. While some studies advocate 8-12 people per focus group (e.g., Robson, 2002; Fisk *et al.*, 2009), we decided to limit the number of participants to 5 per focus group to reflect the fact that we were working with special needs users who face multiple barriers to participation (e.g., mobility, confidence, general health, etc.). The smaller group size also made it more feasible to find a mutually convenient time to meet and was ideally suited to encouraging interaction at a level manageable to our users (taking into account their difficulty in identifying who in a larger group is speaking at any given time, especially where participants also struggled with hearing issues). This view is supported by Inglis *et al.* (2003), who – based on their experience of working with older adults to develop an interactive memory aid - suggest no more than 3 people per focus when working with older adults, taking into account potential issues with their hearing, attention and the ability to follow a thread of a conversation, all of which can potentially hinder their contribution. In another study involving older adults in focus group discussions to explore their perspectives toward low back pain collaborative care by medical and chiropractic doctors, Lyons *et al.* (2013) report on their successful adaptation of the focus group approach and advocate the use of smaller groups (2 – 10 participants) and shorter time periods (about an hour) when working with older adults.

Each focus group session lasted no more than 2 hours and comprised 5 people plus a single researcher/moderator. All focus group sessions were audio-recorded: a verbatim transcription of each recording was subsequently generated and subjected to content analysis (Crabtree and Miller, 1999).

Participants' consent to participate was obtained (see Appendix A.2). Given the potential issue with reading documentation associated with the study, all documentation (including the consent form) was produced in various font sizes and distributed in advance of the study (during the community support group meetings) so that participants could turn to family/support workers to help them read the material and give them a chance to ask any questions before consenting to participate. All information was also discussed both at the community support group meeting and at the start of each of the first focus group meetings. Additionally, participants were asked to fill out (for some participants the researcher assisted with completing the questionnaire) a demographic questionnaire (see Appendix A.3), the aim of which was to collect high level information about their condition including:

- age;
- gender;
- type of AMD;
- number of eyes effected with AMD; and
- number of years since AMD diagnosis.

Of the nine participants with AMD, all were over 70 years of age, with five being over the age of 80. One participant had 'dry' AMD in one eye; two had 'dry' AMD in both eyes; all others had both 'dry' and 'wet' AMD in both eyes. The mean number of years since diagnosis for participants was 8.5, with a range of 6 to 12 years.

Overall, the aim of the focus group sessions was to launch our user-centred research and, in so doing, to start learning about and better understanding various aspects of our target users' lives (in particular, how they cope with living with sight loss), to understand their experience with and attitudes towards (mobile) technology, to help us to effectively plan

subsequent stages of our research in terms of being sympathetic to our potential participants'/users' abilities and needs, to enable us to determine the context and setting of our future activities, and to allow us to engage potential participants for our subsequent research activities. Considering the above, the first focus group session for group 1 and the first two sessions for group 2 were structured to gain insight into participants' views/perceptions on and attitudes towards technological devices per se. Following this, the subsequent focus groups concentrated on participants' coping strategies in terms of living with AMD, the challenges/barriers to day-to-day activities posed by the disease, and their perceived independence and quality of life. The final focus group meetings concentrated on our proposed diet diary application – the aim was to elicit participants' opinions on the proposed technology and related high-level needs and wants. At the beginning of each focus group meeting, the researcher explained to participants what the aims and objectives of that session were, what she anticipated to learn from the discussion, why that learning was necessary, and how it was related to the overall aims of the project. It was anticipated this would once again emphasise how valuable their contributions were to the project and, in so doing, encourage participants to value their own opinions and express themselves openly.

3.3.2 Findings

3.3.2.1 Participants' Use of and Perception on Technology

The first three sessions for each focus group were structured to gain insight into participants' views, perceptions on, and attitudes towards technological devices per se. Of specific note was the enthusiasm with which participants viewed current technological devices in terms of what they can offer individuals with AMD and the potential for such technology to enhance individuals' independence and quality of life. The following quotes exemplify this attitude:

“I find Kindle very useful because I can make the letters big, I can download new things into it [...] I always have something new to read [...] because of large prints I don't have to carry heavy books”.

“Technology has gone on and on and we are behind and now we are in a position where technology can help us”

Another participant added the following:

"I use my computer to Skype my son [...] e-mail [...] researching [...] I wouldn't be without my computer [...] There is nothing you can't find online".

A further, perhaps unexpected but nevertheless encouraging, discovery was the extent and breadth of participants' interpretation of 'technological devices' and/or 'technology'. Besides the most commonly referenced 'mobile phones' and 'laptop/computers', participants also included in the technology discussion ATM machines, digital TVs and radios, Kindles™, microwaves, and washing machines, amongst others (Table 3.1 provides an overview of participants' expressed limitations of, or challenges with, these technologies and their recommendations to improve the accessibility of each technology) .

Table 3-1: A summary of participants' expressed limitations of, or challenges with, given technologies and their recommendations to improve the accessibility of each technology.

| Technologies Used | Limitations/Challenges | Recommendations |
|----------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Computers | <i>"I can't use it at all". "I don't think I would want to use it". "I find it very difficult". "I use it for games mainly; everything else makes no sense to me".</i> | <i>"Bringing letters up would really help". "I would use computers if I could make letters bigger that would really help". "I would really like a talking e-mail".</i> |
| Mobile Phones | <i>"I find difficult to read numbers or go into the menu, too many options". I can't dial a number, because I cannot see what's on the screen". "It's very small plus I don't want complicated thing, just straightforward things". "I would not use a mobile phone but rather my landline... it is easier to use and has bigger buttons, what if I make mistakes".</i> | <i>"I would welcome any type of sound feedback". "Please make the letters and numbers bigger". "I would love to use the phone as a magnifier for instance when shopping". "I wouldn't mind anything that would make my life easier".</i> |
| ATM Machines | <i>"I have never used them. It is very difficult to read what's on the screen". "I wouldn't consider using them, not at my age, it's not safe". "Staff is very helpful at my local bank; "I would never use those machines". "How would I know what's on the screen?"</i> | <i>"If I could use my phone as a magnifier, then I would consider trying ATM machines".</i> |
| Digital TV | <i>"I face great difficulties in working out the TV, mine has 47inch screen but I can't see". "It's very difficult, because for settings there is no sound feedback". "I watch True movies on sky but at the end they never say what happened and it drives me mental". "I never go into settings, and if I accidentally press something I simply switch it off from the power, so I don't do more damage".</i> | <i>"I would try going into the menu with sound feedback".</i> |
| Digital Radio | <i>"It is too complicated and has a controller". "I use my old radio which has only an option for changing channels and I am familiar with it". "I have an old radio and very happy with it, don't need a digital one".</i> | |

| | | |
|------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Microwave | <i>"It is a challenge to use the microwave; I can never be sure about the option selected".</i> <i>"I have to take the food out a few times to make sure it's at the right temperature".</i> | <i>"My coloured bumps make a world of difference, that's how I use mine".</i> <i>"Would like sound feedback especially for confirming my chosen option".</i> <i>"I guess sound feedback would make it easier".</i> |
| Washing Machine | <i>"I find it difficult to read anything on the display and don't know when it has finished".</i> <i>"I mean I manage but with difficulties. And sometimes I use my magnifier to select an option".</i> | <i>"I Would like a washing machine that would say all options on the screen and especially say when it has finished washing".</i> <i>"The beep on mine is difficult to hear, so I would like something else".</i> |

Surprisingly, although all participants had owned a mobile phone for an extended period of time, this technology was the least favoured by them. Participants only used mobile phones for "*phoning taxi service*" and receiving and making "*urgent calls*" when outdoors; mobile phones were never used for casual conversations. Participants' principal concerns or difficulties with mobile phones included overcomplicated functions, small buttons and/or screen size (hence the fear of pressing incorrect buttons) and, most importantly, lack of awareness about the available functionality on their mobile phones. This is exemplified in the following quote:

"I find difficult to read numbers or go into the menu [...], I can't dial a number [...] I don't want complicated thing, just straightforward things [...] I only use it for phoning a taxi".

with another participant adding that:

"I don't use them a lot [...], don't need them [...], they are useless [...], very limited purpose [...]".

Four participants agreed that the only advantage of carrying a mobile phone when outdoors was their increased sense of security. Some also enthusiastically made suggestions for improving mobile phone's accessibility, including:

"[...] I love a system with feel, a phone should have big buttons, even if I can't see them, I can feel them and remember where they are".

"I would welcome any type of sound feedback. I would like to use it for different purposes and wouldn't worry about the attention it might attract [...] would love to use the phone as a magnifier [...] I wouldn't mind anything that would make my life easier".

In contrast, the least commonly owned but most favoured device was a computer. Only three participants owned computers, but their comments emphasised the key role that computers play, and the benefits they gain from using them, in their daily lives:

“It makes you feel part of the world, so you don’t feel isolated. I would not be without my computer”.

Of the three computer-literate participants, only one had used Skype and YouTube. There was some evidence that participants’ lacked knowledge about what features are available on mobile phones/computers – two participants suggested the following, clearly unaware of the fact such functionality was already available:

“I would use computers if I could make letters bigger that would really help”.

“I would really like a talking e-mail on my computer”.

All participants found reading LCD displays, and choosing options on their microwaves, washing machines, etc. rather challenging and so often relied on their “*memory*” and/or “*common sense*”; all preferred to use old versions of the appliances because of their “*uncomplicatedness*” – as highlighted in the following quote:

“Technology is far too complicated [...] so when I go wrong I just switch it off”.

3.3.2.2 Living with AMD

Some of the focus group sessions aimed to discover participants’ coping strategies in terms of living with AMD, the challenges/barriers to day-to-day activities posed by the disease, and their perceived independence and quality of life. Shopping and safe mobility when outdoors proved immense challenges for all participants. Despite this, their views on online shopping varied: while some argued that online shopping would, in fact, limit their independence, this view was not shared by all, as illustrated by the following quote:

“Online shopping makes me independent and its fun [...]”.

A further challenge to and limit on their independence was “*exploring new places*” without someone accompanying them, or “*trying out new things*” (e.g., sewing/knitting). Another concern raised was asking strangers for help when required – for example:

“People can’t tell that you have a problem because you look fine, so unless you ask you won’t be offered any help”.

Despite their limited independence and daily challenges, participants were remarkably optimistic and hopeful about their quality of life, confirming the results of another study considering the quality of life in patients with AMD (Slakter and Stur, 2005). As two of our participants said:

“Quality of life is what you make out of it. You can sit at home and do nothing or accept it and move on [...] we are lucky we can at least see something, and people are trying to do things for us to help us”.

“Independence and quality of life go hand in hand and technology could certainly fit in”.

3.3.2.3 Participants’ Views on the Diet Diary and Similar Applications

The final focus group meetings concentrated on our proposed concept. During these meetings, participants had the opportunity to experiment with a few relevant applications on an iPhone and an iPad in order to give them a feel for the technology and current application designs and to encourage related discussion and feedback. All participants found the interaction with the iPhone very “*challenging*” and “*frustrating*” due to its limited screen size, touchscreen sensitivity, and “*overloaded*” interface with small icons.

In comparison, the larger iPad received a positive response from all participants who considered its advantages to include the “*larger screen size*”, “*larger icons*”, and the fact that it is “*lightweight*” but “*portable*” and “*mobile*” (yet with a prospect of being used as a “*desktop computer*” whenever necessary). An important issue raised by one of the participants (who also had arthritis) was that the majority of individuals with AMD also have other health concerns often as a consequence of their age (Ramkumar *et al.*, 2010). This means that the visual element of UI design should not be the only concern for designers of technology for individuals with AMD: for instance, individuals with arthritis are likely to experience greater difficulty with touchscreen sensitivity and, to combat this, participants suggested the use of “*pens*” (i.e., styli) for input to overcome the limitations associated with touchscreens.

Participants were very keen on the concept of our proposed application. For it to yield positive outcomes, participants suggested consideration of the following: a “*detailed instructions “booklet”*”; “*color-coded buttons/icons*”; white foreground colour on black background; the “*possibility for customisation (e.g., increase font size)*”; and “*speech input*”. Encouragingly, our participants had a positive and inclusive reaction to our proposed application – for example:

“It could become my best friend. It would become my companion, give me an incentive and fill my day. [...] I am gobsmacked to what technology can do and that I can be part of it”.

3.3.3 Discussion

The focus groups were well suited for our initial, participatory field-based exploratory knowledge elicitation activities, rendering rich data about participants' experiences, opinions, needs and viewpoints. As suggested by Leung and Lumsden (2008), working with an existing support organisation was critical (a) to finding and recruiting participants, and (b) for conducting meetings in an environment in which participants were comfortable and familiar. In particular, the ability to form and conduct the focus groups around existing communities established an effective atmosphere for stimulation and encouragement of group discussion. Despite industry advances in making mobile phones more accessible for the visually impaired, it was apparent from our focus group discussions that such devices are not yet fully accessible or acceptable to people with AMD. In particular, the size of the display is a key limiting factor for this user group; the loss of central vision makes it very difficult to see fine details, especially important details placed in the centre of the display, with the result that they find the “*small*” screens of mobile phones rather challenging. We identified an imperative need for intuitive and consistent design so that participants can rely on their memory if and when necessary (reflections on these observations are evident in our UI design – see later). Participants also stressed the importance of speech and audio feedback for any type of technology to improve its accessibility. Despite issues with current technology, participants' enthusiasm towards technology, even from this early stage, was encouraging and promising: mutual learning throughout the subsequent stages would be fundamental for the endurance and success of the project, and this reassured us about participants' willingness to learn.

Their positive interaction with computers (for those participants who owned computers) and positive and encouraging feedback about the potential of (assistive) technologies demonstrated that older adults with AMD could and would use technology if the potential

benefits of such use are easily understood and appreciated. In fact, a recent study evaluating older adults' readiness to adopt health-related technology concluded that a key motivating factor is perceived usability (Heart and Kalderon, 2013). Subsequently, in response to these findings, in our follow-up studies (see Section 3.4 and Chapter 4) we were keen to focus on the perceived usability of our proposed diet diary application, particularly since participants were concerned about the lack of nutritional guidance and appropriate support currently available to people with AMD for supporting their eye health.

Encouragingly, our participants had a positive and inclusive reaction to our proposed application; there is significant potential not just for positive impact associated with the use of mobile assistive technologies in vulnerable older adult communities, but also for their enthusiasm to be part of the evolution of such technologies.

These focus group meetings established a friendly atmosphere where individuals' contributions were stimulated and encouraged; in turn, this enabled the researcher to introduce the project and its goals informally yet effectively, and to recruit participants for subsequent stages of the project. While research concerning older adults' participation in focus groups suggested possible challenges in retaining their focus and attention during group discussions (e.g., Antona *et al.*, 2009), we would argue that such informal exchange between participants should, in fact, be encouraged during group discussion: we found the occasional tangential discussion and social elements of the focus groups to be particularly beneficial for developing interpersonal bonds and establishing rapport with the researcher. This, in turn, helped us to attain an understanding of their shared perception both in terms of AMD and attitudes/expectations towards assistive technologies. Since each focus group comprised several participants and only one researcher, we believe that participants felt comfortable and encouraged to interact in terms of sharing ideas and experiences – a proven indicator of the quality of output from a focus group (Barrett and Kirk, 2000).

As the participants learned to trust the researcher, they become increasingly candid in their discussion of the challenges/barriers to day-to-day activities posed by the disease and their experiences of living with the impairment. Whilst the social element of their participation and discussion was empowering for the participants (see Chapter 5), the discussion at times was challenging emotionally for the researcher who developed immense empathy for the individuals with whom she was working.

Notably, the researcher learned that participants acknowledged the need for our proposed technological solution and would use it if it was designed to compensate for their visual (and other age-related) deficiencies – giving a strong route in to engage them further in this research. This further cemented the need to place anticipated end users of assistive technologies in a central and inclusive role in the design of such technology.

3.3.4 Study Limitations

While the focus groups – representing the initial knowledge elicitation stage of an ongoing research agenda – successfully contributed qualitative and previously unstudied information about the attitudes, needs, wants and capabilities of individuals with AMD as they relate to information technology, they were not without their limitations (albeit some of which were unavoidable).

The self-selected convenience sampling and limited population sample size used for this study means that the findings may not be entirely representative of the general population of individuals with AMD (i.e., those with different backgrounds and life experiences, or those who did not seek out or attend a support group). The findings articulated above are based primarily on a study conducted with a group of motivated individuals who had taken the initiative to engage with their local Macular Support Group. Thus, it is possible that these individuals were uniquely approachable, ‘socially active’, and shared common views and expectations that may not be otherwise reflected across the general AMD population. In contrast, individuals who choose not to engage with their dedicated community support

groups or who opt out of being registered on a visual impairment register, may have differing views on their impairment and quality of life and, as such, may have additional or alternative needs and expectations in terms of assistive technology design and development. Furthermore, only one male participant took part in the study, reflecting the fact that about twice as many females over the age of 75 have AMD compared with males of the same age (Patient, 2015); and more females than males tend to use the services of the Macular Society or healthcare in general. Having said that, it is anticipated that participants who took part in the study are more likely to engage with technology as early adopters, who can then advocate to others – the more late adopters – within their community about their perceived benefits of using technology. This mirrors society in general, where, according to the theory of diffusion of innovations (Rogers, 2010), early adopters of new products (technologies) play an important role by influencing the attitude and changing the behaviour of the later adopters.

To take advantage of familiar territory for the participants and to avoid barriers associated with participants travelling to the sessions, focus group meetings took place in coffee shops. Albeit comfortable for participants in terms of environmental awareness, the noise and distractions therein were outside of the researcher's control and this occasionally placed an additional load on the focus group team – it was harder for the researcher to accommodate participants' deficiencies (in particular issues with hearing) and it was at times harder (than it would have been in a quiet space) for participants to communicate efficiently. In light of these considerations and with ongoing immersion within the AMD community, subsequent (group) meetings (e.g., participatory design sessions discussed in Chapter 4) were conducted either in the participants' homes or within the University. That said, great care was taken to ensure that the study was conducted as planned and expected by participants; the researcher believes she was successful in this respect, and did not find any evidence of negative impact on the reported findings because of the stated limitations.

It could be suggested that the presence of the researcher (moderator), who was much younger than the participants and had not experienced the challenges of living with AMD,

influenced the way participants reflected on or articulated their experiences. Nevertheless, within a short period, she gained trust of the participants leading to honest open discussions. In fact, it is felt that the presence of the researcher heartened participants, who felt appreciative that someone of a much younger generation was interested in their needs and opinions.

3.4 Phase 3: In-Home Observational Studies

Emerging from the focus group discussions was a realisation of the true extent of heterogeneity of individuals' capabilities, experiences of living with AMD and, as a result, the significant differences in their needs in terms of acceptance of assistive technologies. It felt imperative to gain a deeper understanding of participants' daily coping strategies and what it is like to live with AMD. In order to acquire this understanding, a series of in-home direct observation sessions with older adults with AMD were conducted; It was anticipated findings from these would usefully supplement and extend the qualitative findings from the focus groups.

Direct observation techniques draw on ethnographic methods and involve observing participants as they conduct activities within context. For this study, the aim was to observe daily in-home activities of older adults with AMD in an attempt to gain an insight into their contextually-relevant real life experiences and coping strategies (Goetz and LeCompte, 1984). Observational studies typically support an enhanced understanding of the relationships between observed participants' behaviours, challenges, preferences and needs (Antona *et al.*, 2009).

Other researchers have recognised the usefulness of direct observations for knowledge elicitation when, for instance, working with blind users (Shinohara, 2006) or users with cognitive disabilities or aphasia (Davies *et al.*, 2004). It is also claimed to be another of the very few research methods that is appropriate for use with older adults and participants with impairments without requiring methodological modifications or adjustments (Antona *et al.*,

2009). Little is documented, however, in terms of the practical application of direct observations for the purpose of knowledge elicitation with such communities of users: most research to date has tended to overlook reflections on study design and processes in favour of a focus on documenting qualitative study findings. One project which *has* elaborated more on the practical considerations for carrying out this type of research is the UTOPIA (Usable Technology for Older People: Inclusive and Appropriate) project (Dickinson *et al.*, 2003), which argues for knowledge elicitation activities to be conducted in the homes of older adults (with impairments). Their recommendations for conducting such activities include: being mindful and sensible of the hopes and expectations that an older person might have of the researcher; creating a relaxed social atmosphere where the participant feels at ease; clearly communicating the researcher's role and potential benefits to the participant from taking part in the study; and finally, careful consideration of any ethical issues, in particular to not cause any distress to the participant(s) because of unrealistic expectations.

Reflecting on the learning from the focus groups and emergent understanding of observation methods with older adults, it was considered essential to attain a true sense of 'being there' with representative participants, valuing the opportunity to experience their daily life via a series of in-home observation sessions. It was anticipated being in a familiar and comfortable environment would empower participants to feel more in control and exhibit behaviours (e.g., interacting with a remote controller or a microwave) and reactions (e.g., when the interaction with the remote controller or the microwave is challenging or effortless) that would otherwise be difficult to discover when engaged in one-to-one or group discussions out of the home context.

3.4.1 Study Design and Participants

The purpose of this phase of the project was twofold: (a) to gain a detailed appreciation of participants' daily coping strategies and what it is like to live with AMD; and (b) to appreciate their technological needs so that their daily coping strategies could be ideally modelled in such a way as to facilitate mapping of relevant concepts into the design of the proposed

technology. To do this, a series of in-home observations were conducted over the course of three months. 4 participants were recruited from the focus groups (one male and three female) who were particularly eagerly engaged with the process and willing to participate in this next phase. In recognition of their vulnerable status and for reasons of professional indemnity, participants were strongly advised to invite a third party whom they knew well (e.g., family member, friend, carer, etc.) to be present while the observations were taking place; where participants decided not to have a third party present, they were asked to provide details of a person to contact in case of an emergency. As the researcher was visiting older adults in their homes, she was in constant contact with her supervisory team in order to communicate details of her itinerary and appointment times - a text message was also circulated just before and after each meeting informing the supervisory team that the schedule of work had been completed.

In total, 6 observational sessions were conducted; the number of sessions conducted per participant was determined by availability and also by professional judgment as to whether additional sessions with the given individual would elicit new data (i.e., a judgement as to whether data saturation had been reached); each session lasted no more than an hour. Observations were kept very informal to ensure participants felt at ease: handwritten notes were taken (and later analysed to identify themes and main categories) with reference to the physical environment, the activities participants engaged in, how they interacted in the setting, and what enlightenments they provided on their actions and living arrangements in general.

At the beginning of each session, the researcher ensured that all participants fully understood the purpose of this phase of the study and reminded them what was involved in taking part. They were encouraged to take no notice of the researcher and continue with their normal daily activities. Mostly, participants were observed in their living rooms (or main sitting areas), but some invited the researcher into the kitchen to observe them whilst preparing food. At all times, the researcher tried to remain as unobtrusive as possible to ensure comfort

of the participants; she refrained from ‘interviewing’ participants, but engaged in discussion with each participant as befitted the situation.

3.4.2 Findings

A number of prominent trends or commonalities were noted across all observed participants in terms of their living arrangements with respect to accommodating their visual deficiencies. These included having well-lit and simple interior design, light-coloured walls, a lot of lighting in every room, coloured ‘bumps’ on most appliances and switches, and preferably no stairs (only one participant was living in a house with stairs and found them very challenging, especially going down the stairs, as everything appeared in “2D” (i.e., ‘flat’)). She noted:

“Everything is very slow, it is like learning all over again. I get my magnifier glass to check if the house is tidy. But I can’t see everything to clean”.

Furthermore, participants typically kept their homes very tidy, organised and, most importantly, kept things “*handy*”. For example, all participants had a small table or chair in their living room on which they kept “*everyday things*” such as medication, razors, remote controllers, glasses, magnifiers, and emergency contact numbers. In their kitchens, all jars, cans and bottles were organised and out on display to eliminate the need for looking into cupboards and enable them to see/find things more easily. Participants were generally inclined to put things back where they belonged (in the same place every time) so they knew without thinking where to find things. Being organised was generally considered crucial for maintaining an independent life – as illustrated in the following quotes:

“I always keep it tidy, neat, so I can find it, I keep everything organised, I am much more organised, [...] you have to be organised, that’s the only way you can survive”.

“I can only see movement; I keep everything tidy in place. I keep medication in hand, keep everything in order. [...] I Keep the trousers, shirts, coats/jackets separately to make it easy to find things”.

The main difficulties encountered by participants at home included losing things and/or friends/relatives misplacing things when trying to help. Three participants were observed whilst preparing food in the kitchen. While, surprisingly, no notable differences were observed between their cooking methods and that of a sighted person, they did have to adapt their working methods in the kitchen. For example, one participant explained:

“With the kettle I count to 5 so I know that its ready. [...] On the cooker, I literally have to keep my nose close so I know which hob is the slow cooking which isn’t. [...] I have talking scales”.

One participant also explained that with “normal” vision she would use scissors instead of a knife to ‘cut’ vegetables (reason being that using scissors required the use of both hands and more precision), and another participant noted the challenge associated with ‘seeing’ what was on a plate when eating. One participant also stressed the challenges involved in being “outdoors”, where “things are outside of their control” and “change rapidly”. In particular, she noted shopping as one the more challenging tasks to undertake when outdoors, saying:

“I do go out, but food shopping is pain, so I only pick up things I absolutely know, as otherwise I have to hold items very close and breath on them, and I do not like that , I would not want another person doing that to a food I want to buy”.

In terms of observed use of technology in the home, two participants owned computers and used them primarily for e-mailing and “researching”. In both cases, the participants’ e-mail accounts were constantly logged in and were one-click away via the desktop. We observed considerable differences between their approach to interaction with a desktop computer and with portable devices/objects. While the desktop required no ‘special viewing’ technique (participants were sitting close to the screen and looking ‘straight’ at it), both participants had to hold portable devices/objects (e.g., Kindle™, book) slightly to their left side and under a lamp to be able to read. Participants also preferred yellow font on black background when reading digital books, newspapers and magazines.

Similar to the findings from our focus groups, despite their limited independence it was encouraging to observe that participants “had control” over their own lives and were positive and anticipative about their quality of life – for example:

“When my husband died I was on my own. But decided to do something about it. In order to go to Solihull [support group for Macula] I have to take a long journey so that the bus can drop me on the same side that picks me up, because there is no crossing”.

And:

“If I could see, I would be having the time of my life, I have the energy, time, but I don’t have the confidence to go on plane and see new things, but I always think that there is someone worst off than you”.

Another participant, who was the eldest of the participants being observed, discussed his “*music notes*” (all printed on yellow paper with large print) with great attentiveness, and discussed how playing the violin is still one of the great pleasures in his life, and that his impairment could not “*take that away*” from him. He later played the violin for the researcher with great delight and explained:

“I Play music by ear, so I have to listen to the music on my computer and then try and play it on my violin. [...] you know I have to rely on my memory a lot, I never knew my national insurance number, but learnt it now”.

3.4.3 Discussion

The majority of participants lived on their own and, perhaps because they had taken part in the focus groups, seemed to regard the in-home observational phase as more of a one-on-one interview, where they felt obliged to provide detailed enlightenment on their living arrangements and were keen to engage in social conversation. Thus, for some participants the first visit was simply used to listen to their life stories, some happy, some sad. Although emotionally challenging for the researcher, the appreciation they showed was sometimes overwhelming, and this certainly helped to further establish a trusted relationship between the participants and the researcher. It was, to start with, challenging to establish an observational arrangement in which participants were encouraged and able to take no notice of the researcher and continue with their normal daily activities. Although it was a challenge for participants to appreciate the value of silent observation, by wanting to help and substantially contribute they provided lots of valuable explanations for their actions (as demonstrated by the quotes reported above). It was important for the researcher to reassure participants of their great help and be an active listener.

Findings from this study indicate that an important consideration when designing for people with AMD is the environment where technology is going to be used. The observational studies showed that lighting levels and distance from screen can greatly influence the perceived usability of a device (an arrangement that was later echoed when choosing the setting for our participatory design (PD) sessions – see Chapter 4). Thus, technology design was deemed to need to accommodate different viewing distances rather than assume a one-

size-fits-all solution. Contrast sensitivity is significant when designing for people with AMD (as testified to in large part by the colour schemes within their homes): participants' comments advocated the need for a white and/or yellow foreground (i.e., icons, buttons, font) on black background. Findings further suggest that usability may be enhanced by avoiding unnecessarily colourful displays yet, conversely, carefully colour-coding high-contrast buttons and icons: the black 'circle' at the centre of their vision makes it impossible to differentiate dark/similar colours close to each other or on top of one another.

A dependence on memory and consistent layout of their living environments was noted as being of utmost importance to this user group and this finding should translate to any technology design. It is interesting to note that their desired reliance on memory is in direct contradiction of the recognition rather than recall mantra to which we typically conform in technology design; although consistent design, layout and navigation are important elements of any user interface design, they are a vital necessity for this user group and it was recognised that this had obvious implications for the automated UI layout adaptation algorithm we were to develop to accommodate their degenerating capabilities. Our observations highlight the importance of training users in the use of technology. Talking to and observing our participants highlighted the fact that comprehensive instructions on setting up and using any form of technology can help users to become more familiar with equipment and its available functionality, and also to understand how it can fit into their daily routine. This can further help in minimising their fear of making a mistake, our findings revealing that this is one of the main reasons individuals with AMD are reluctant to use new devices.

Results from this study also illustrated the importance of considering how individuals' visual acuity affects their interaction style. During the observations it was noted that participants positioned books and other devices (e.g., Kindles™) to maximise vision via their "*better*" eye. Based on this, we believe that accommodating the "*better*" eye (i.e., the one not affected by AMD or the one with better peripheral vision) is an important consideration for UI layout for individuals with AMD; this largely depends on participants' adopted viewing techniques.

Overall, the in-home observations successfully provided a perspective on the lives and context of living of our participants that would not otherwise have been possible; they further cemented the trusted relationship between the researcher and participants such that the latter were increasingly committed to seeing the participatory research through to its conclusion.

3.4.4 Study Limitations

Some of the limitations (i.e., the self-selected convenience sampling, limited sample size, male and female ratio, and motivations for taking part in the study) identified in relation to the focus groups, are also pertinent for the observational studies. This again means that all the observed participants had positive outlooks on life and, as such, the researcher was not able to engage with and observe individuals who are not necessarily managing as well with their impairment and might, therefore, have very different views on their quality of life and attitudes towards technology and very different 'coping strategies'.

By limiting the observations to in-home only, the researcher has possibly overlooked how individuals with AMD perform tasks (and cope with AMD) in more complex situations (e.g., when outdoors or shopping). That said, they are often accompanied when in more complex environments, so observation in-home was a true observation of their independent capabilities. Furthermore, it felt that observing participants in public settings may have caused them significant discomfort and stress which was not deemed necessary to achieve the goals of this study.

3.5 Summary

Findings from this chapter suggest that, due to the heterogeneity of individuals' capabilities both across and within given visual impairments, multimodality and maximal flexibility need to be a priority in user interface design so that users can personalise systems to their individual needs and capabilities, taking into account their rate of degeneration. In particular,

multimodality has significant potential to not only compensate for visual deficiencies but to also accommodate any comorbidity issues. Studies reported in this chapter suggest that individuals with AMD need more time to locate and identify things on screen which stresses the importance of providing the ability to customise aspects of the user interface such as optimal font and icon size and placement, and extended timeouts to support effective identification of visual content.

As a result of the degenerative nature of the disease, changes in individuals' visual capabilities will adversely and changeably affect their interaction with technology over time. Thus, the design of the UI must be capable of making allowances for trial-and-error and of identifying and adapting to users' vision changes over time.

The exploratory fieldwork activities reported in this chapter confirm that current technological devices are not generally designed with vulnerable adults in mind, but also endorse suggestions in terms of the positive impact that technology can have on this user group if designed based on their needs and wants.

This chapter has demonstrated how existing support groups for people with AMD are an ideal vehicle for establishing contact with the community and recruiting participants for studies. While it could be argued that this approach could be time consuming and challenging, the benefits gained for both the researcher and the participants are substantial and worth the effort: the researcher gained insights into the needs, views and concerns of target users, whereas the participants benefitted from the opportunity to contribute to the design and development of the next generation assistive technologies for their use. Participants recruited via this route tend to understand and appreciate the challenges which they face and are, generally, willing to discuss personal problems to comfort other members or be of assistance to future generations (this includes taking part in research studies). Additionally, this creates an effective atmosphere for knowledge elicitation wherein participants already know each other from local AMD support groups and thus feel

comfortable to stimulate and encourage group discussion. This level of engagement enabled the researcher to discuss sensitive issues such as participants' coping strategies in terms of living with AMD, the challenges/barriers to day-to-day activities posed by the disease, and their perceived independence and quality of life. The following chapter illustrates how the aforementioned understandings and considerations were incorporated into the participatory design of the proposed diet diary application.

Chapter 4. Phase 4: Participatory Design of the Diet Diary Application

4.1 Introduction

As discussed in Chapter 2, participatory design (PD) approaches are not being adopted in practice for the design of technology for special needs user groups as broadly as they arguably should, or at least could, be despite their potential benefits (as reported in Chapter 2). More specifically, as we have illustrated, there is little evidence of such methods being applied to the design of technology for the visually impaired, including for people with AMD. Combining our motivation to address the needs of people with AMD via our proposed diet diary application with our desire to include them directly and effectively in the design of the technology, this chapter reports on our adoption of an adapted PICTIVE (Muller, 1992) participatory design approach to inclusively create paper prototype designs of our proposed application for users with AMD to support their dietary-based AMD progression retardation over time. It reports on the design activities we conducted for the purpose of informing the development of the diet diary application for older adults with AMD, and so focuses on the tangible outcomes (in essence, prototypic designs and identified user requirements) of the

process. Finally, participants' reflections on being part of the process and findings from preliminary evaluations of the paper prototype design are also discussed in this chapter.

4.2 The PICTIVE Approach

A semi-formalised example of a PD approach is the PICTIVE (Plastic Interface for Collaborative Technology Initiatives through Video Exploration) method – a paper prototyping technique which utilises common office supplies (e.g., coloured paper, pens and Post-It™ notes) to produce paper prototypes of user interface designs (Muller, 1991). The use of inexpensive, familiar, and easily-manipulated materials to generate paper prototypes of designs encourages everyone on the team to contribute equally and fully and, as such, empowers them to become integral members of the PD group – that is, they became full and active members of the design team for the purpose of hands-on design of technology. This, in turn, creates an informal, friendly atmosphere encouraging the sharing of diverse ideas and insights. It relies on video technology as a means for recording design sessions and, in so doing, makes the 'record-keeping' of the sessions relatively easy. The tangible outcomes of PICTIVE PD sessions are (a) paper prototype designs for the technology, and (b), as a result of the recorded activities and prototype designs, a rich set of elicited user and associated software requirements.

An example of the successful use of the PICTIVE PD method to design technology with a special needs user group is the work by Lumsden *et al.* (2005), who designed a mobile application to assist functionally illiterate adults to cope with literacy-based tasks in their daily lives. They report on how, when tailored to a project's needs, the PICTIVE method can be a valuable tool for design activities involving participants with impairments (or adults with limited literacy skills in their case) (Leung and Lumsden, 2008). This view was also supported by Massimi *et al.* (2007) who used participatory (PICTIVE) activities with older adults to transform an off-the-shelf mobile phone into a specially-designed memory aid. Their experiences, which are consistent with those already discussed in Section 2.5.3, confirm the potential benefits of engaging older adults (with impairments) in the design and development of technology to support their specific needs.

Encouraged by the laudable success of the aforementioned studies (including examples discussed in Section 2.5.3) where PD approaches have been comprehensively and beneficially adopted for the design of technology for special needs users groups, we decided to adopt the PICTIVE PD method for our own research because its central tenets are (a) the inclusion of end users as equal and valued members of the design team, and (b) the use of common office supplies rather than text documents or computer software (Muller *et al.*, 1993) as the design medium. We felt these underlying tenets made the method well suited, in principle, to our user group and, since we anticipated that taking part in design work was a new, and perhaps initially overwhelming, task for our participants, we felt the method had considerable scope to empower (further discussed in Section 5.4) them to feel relaxed and able to contribute to the design work without prior technical expertise or experience.

4.3 Recruitment and Participants

Based on our knowledge elicitation activities we were armed with rich background knowledge and initial ideas for assistive technology for the AMD community, and had acquired a deep and relevant understanding of the needs, difficulties, and viewpoints of individuals with AMD. We therefore invited 4 already-involved individuals (comprising 3 with AMD and a carer who also had AMD – see Table 4.1) to become integral members of our participatory design (PD) group – that is, they became full and active members of the design team for the purpose of democratic hands-on design of technology to support their healthcare and independent living needs.

Table 4-1: *PD participants' characteristics.*

| ID | Age | Gender | Experience with Computers | AMD Severity |
|----|----------|--------|---------------------------|----------------------|
| P1 | Mid 60s | Female | Moderate | Dry in one eye |
| P2 | Late 70s | Female | None | Dry/wet in both eyes |
| P3 | Late 80s | Female | None | Dry/wet in both eyes |
| P4 | Late 80s | Female | Some | Dry in one eye |

We selected these individuals on account of their by-now-established rapport with the researcher, their demonstrated keenness to contribute to our research agenda, and their

comfort in interacting (as a consequence of growing interpersonal bonds) with each other. For a participatory design team to work well, interpersonal engagement and commitment to cause are essential and we were in an ideal position to hand select our participants for this more intense level of participation having engaged in different ways with them already during our knowledge elicitation activities and therefore knowing them each as individuals.

Comprising members of different ages, different stages of visual impairment (although some participants reported having the same type of AMD, the severity of visual impairment varied greatly), and different levels of IT literacy, we believe our participatory design team was representative of the heterogeneity of the AMD community whilst being ideally sized to encourage active participation (the number of participants in such studies in general and, in particular, in successful previous studies with special needs users (e.g., Massimi and Baecker, 2006) are typically in this order. We were delighted to have successfully recruited a team of this size, since finding and recruiting participants with special needs to such studies can be challenging (as reported in other research (e.g., Leung and Lumsden, 2008)); this is particularly true of people with early diagnosis of AMD who often experience some degree of denial and who are not ready to self-identify and engage in support networks for AMD, placing them out of reach for studies of this nature (Stevens *et al.*, 2014).

Given the potential issues of vulnerability associated with participants' capacity to read documentation associated with the study, as per our practice in previous phases of the study, we paid particular attention to valid mechanisms for fully informing them about the work and obtaining their consent to participate. To this end, all documentation (including consent forms (see Appendix B.1)) was produced in various font sizes and distributed in advance of the study so that participants could turn to family/support workers to help them read the material and give them a chance to ask any questions before consenting to participate; all information was also verbally explained to all participants. . As reported in Chapter 3, ethical clearance for this phase of the study was sought from the Aston University Research Ethics Committee (REC) (see Appendix A.1).

4.4 Study Design

Over a period of 5 months, participants attended 8 design meetings in order to directly contribute, in an empowered way, as experts in living with their condition to the design of our mobile application. Since the PICTIVE PD process advocates that all participants should have equal stake and ownership of the process and the outcome, we opted for a relaxed structure to encourage participants to drive the process rather than being led through it. Although we had originally planned to constrain sessions to approximately 2 hours to avoid fatiguing our members, participants were repeatedly deeply engaged in the process and so were always keen to continue their design work for longer. To this end, we encouraged participants to dictate the length of time they were willing to commit to the session, placing them in control. Consequently, the sessions typically lasted 3-4 hours.

The design sessions took place at the University, in a room chosen for ease of access and good lighting. To remove physical participation barriers associated with commuting, return taxi-based transport was arranged (and funded) between participants' homes and the University. Participants actually commented that they enjoyed conducting this type of work within the university environment. To them, this reinforced the importance of the project and the significance of their contribution; it was regarded as highly motivational and made them feel "*very important*" individuals (as is further discussed later in this chapter).

During the design sessions, participants were comfortably seated around a shared design surface on which they worked (see Figure 4.1). All sessions were recorded by a camera (to which participants had consented); the area captured by the camera was delineated in blue tape (see Figure 4.1) on the design surface to ensure all relevant activities took place in view and to allow participants space to work 'off the record' if desired.



Figure 4-1: *The shared workspace delineated in blue tape.*

At the beginning of each session, the session goals were identified. Each session commenced with a summary of the previous session to recap the group's achievements as

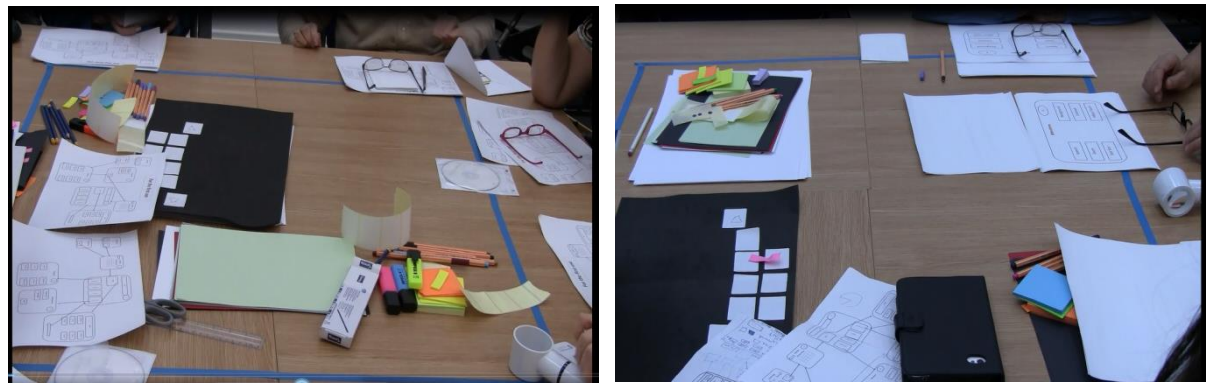


Figure 4-2: *Participants' individual copies of the prototype design.*

part of on-going encouragement given to participants and reinforcement of the value of their contribution and the fact that their healthcare and independent living goals are the driving force behind the design. As a concession to their visual impairment, rather than force participants to only view the central working version of the design, the researcher also created individual copies of the design for each participant (see Figure 4.2 for examples) to enable them to better and more comfortably view the content (this often necessitated holding the design at an angle next to their stronger eye – a viewing method which was uncomfortable if applied to the large, central copy of the design).

4.5 Prototype Design

The first session was used to watch an explanatory video¹ on the PD approach and to allow participants to ask questions which successfully relaxed them into the process. This was a very useful and practical method for introducing how PICTIVE sessions would proceed and for illustrating how simple office materials could be utilised to co-design paper prototypes. Additionally, we briefly explained to participants how these sessions allied with the overall scope of the project, what the subsequent stages would be and what the overall expected outcome was. We felt this to be essential for avoiding any mismatched expectations.

4.5.1 Hardware Choice

As already discussed, it was apparent from our knowledge elicitation activities and ongoing discussions with our participants that they still encounter lack of motivation and many learning difficulties with using mobile phones. In particular, the size of the display is a key limiting factor for this user group; the loss of central vision makes it very difficult to see fine details, especially important details placed in the centre of the display, with the result that they find the “*small*” screens (and components contained therein) of mobile phones rather challenging. Consequently, we dismissed standard smartphones as our hardware choice, and from the first design session, agreed to focus on tablets instead. Participants identified some important features to be taken into consideration when selecting technology, namely that selected technology needs to:

- be lightweight and portable (hence our choice of mobile device);
- be easy to grip and hold (in particular for people with arthritis);
- be easily chargeable and to have reasonable battery life;
- support loud volume and vibrational output (in particular for people with hearing impairments);
- be hearing aid compatible; and
- support the taking of photographs.

¹ https://www.youtube.com/watch?v=4npftEf3_n4

4.5.2 Paper Prototyping

Given the nature of our target audience, accessibility was at the heart of most design sessions. Initially, we began with a discussion on choice of colours, in particular the black/white foreground/background issue raised during our focus groups. We passed around both white and black paper onto which each participant could place some interface components (in the form of Post-It™ notes) in order to compare contrast effectiveness (see Figure 4.3).

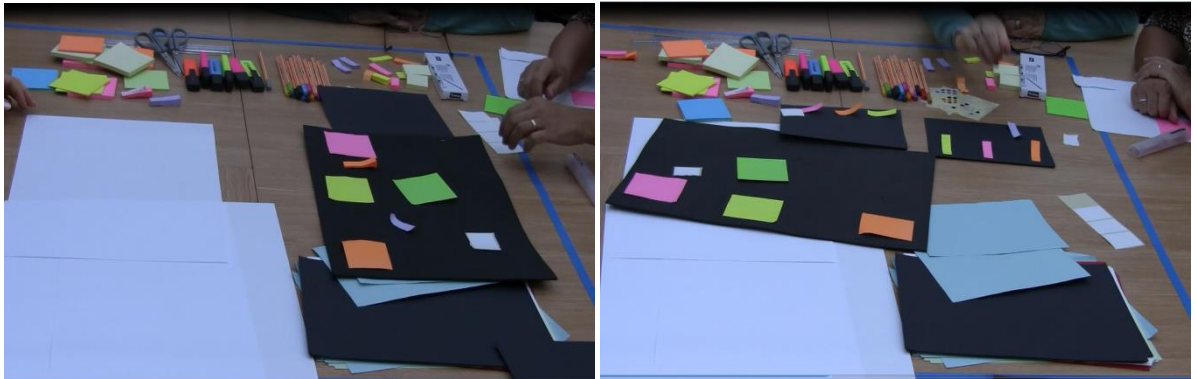


Figure 4-3: *Participants comparing contrast effectiveness of interface components.*

It was apparent that the black background was most beneficial to those participants with the worst vision, whereas two participants with better eyesight (including the carer) preferred the white background. All participants (except the carer, who had early onset AMD) placed the components around the edges of the interface and left the centre clear; they also found 6-7

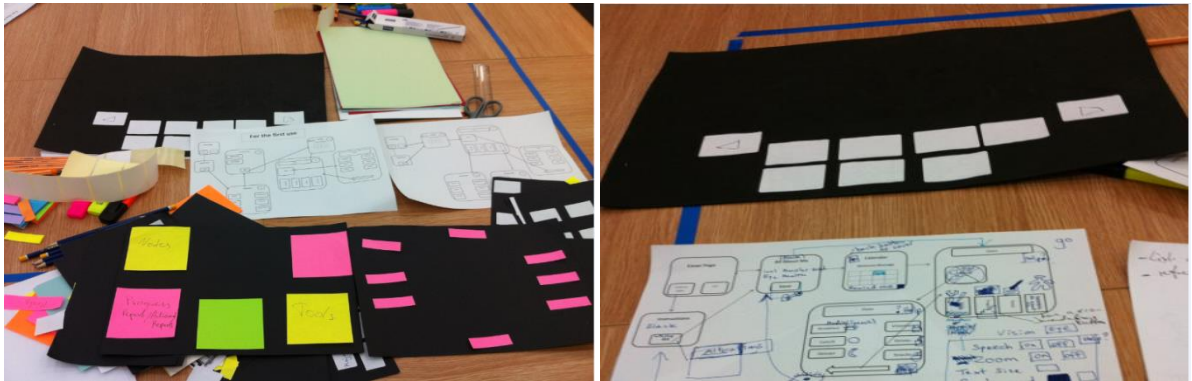


Figure 4-4: Participants' arrangements of the UI components.

components per screen to be manageable (see Figure 4.4) – a key design finding only possible as a result of including users with late stage AMD. This activity afforded us an excellent and timely opportunity to expand on the prospect of personalisation – that is, how participants could individually tailor the application to better serve their needs and maximise application accessibility.

Since personalisation of the application was identified as a core requirement, we discussed, and participants strongly agreed to, the idea of presenting users with the option of completing automatic eye tests when they first open the application. This information would be used to personalise the interface to start with; thereafter, users would always have the option of manually 'altering' the settings. Participants embraced the concept of personalisation and insisted on entering their name to receive a personalised welcome message, as reasoned by the following quote from one of the participants:

"I would think then at least someone is thinking about me. It makes me feel happy and sounds nice".

Following this, participants expressed the need for a brief instructions option on the first screen (in addition to manual instructions). As highlighted during our in-home observations, our participants preferred to carry out tasks in a logical order or predefined sequence and so we adopted the same approach to our PICTIVE prototyping (Figure 4.5 demonstrates how

participants applied hierarchical structure, and Figure 4.6 shows the logical order participants followed to design the paper prototypes): that is, having discussed the 'Welcome' screen we progressed to the next logical screen (the 'Instructions' screen) deemed essential by all participants. Having considered the requirements for launching or opening the application, we moved on to consider what was referred to by two participants who were slightly more computer literate as the 'home page' or 'main menu' for the application.



Figure 4-5: *Hierarchical structure of the paper prototype.*

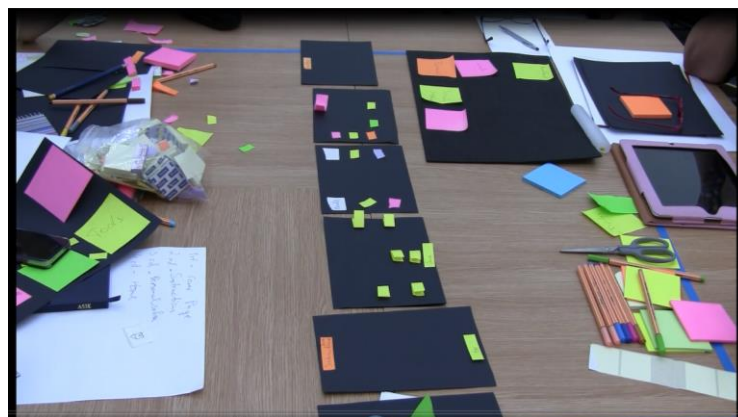


Figure 4-6: *Logical order of the prototype design.*

Since participants found 6-7 icons per screen to be manageable, we limited the number of options per screen (including the main menu screen) accordingly, and this, to some extent, determined the overall system functionality.

After much deliberation, participants agreed that the 'Main Menu' screen should comprise: (1) an option (later named 'Calendar') for viewing the calendar and selecting dates for food entry; (2) an option ('Progress') for viewing their progress made in terms of adherence to dietary recommendations, and for accessing their recommendations (it is important to note

that recommendations would be automatically updated based on user's food entries); (3) an option ('Notes') to 'store' their 'ideas' and thus support their memory; (4) an option ('About Me') for recording a user's personal data (e.g., age, health condition, dislikes) for the purpose of providing customised dietary advice and recommendations; (5) an option ('Alterations') for altering or making changes to the screen and personalising it; and (6) as the key focus, an option ('Food & Drink') for recording their daily intake of food. Together, we designed paper prototypes to reflect the main menu and subsequent screens which the researcher later converted into higher-fidelity versions using PowerPoint (see Figures 4.7-9 for an illustration of how the paper prototypes evolved during the process from a paper-based design of the 'Main Menu' screen (Figure 4.7) to the higher-fidelity version of the 'Main Menu' screen (Figure 4.9)).

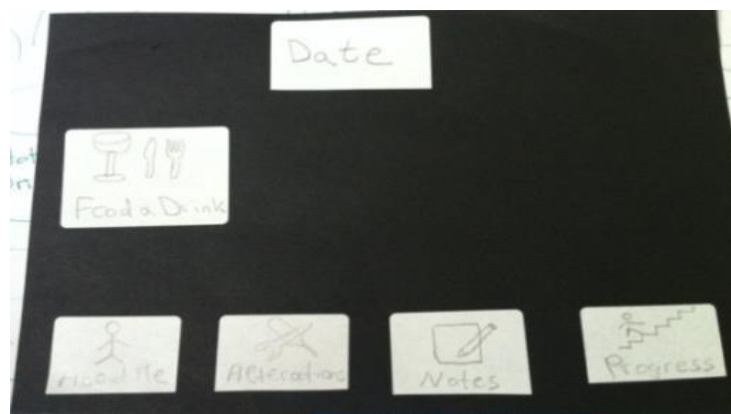


Figure 4-7: The paper prototype of the 'Main Menu'.

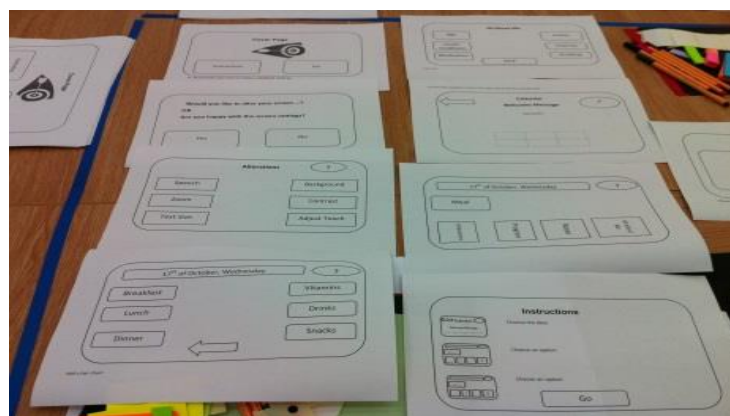


Figure 4-8: Sketches of some of the screens created by the researcher.

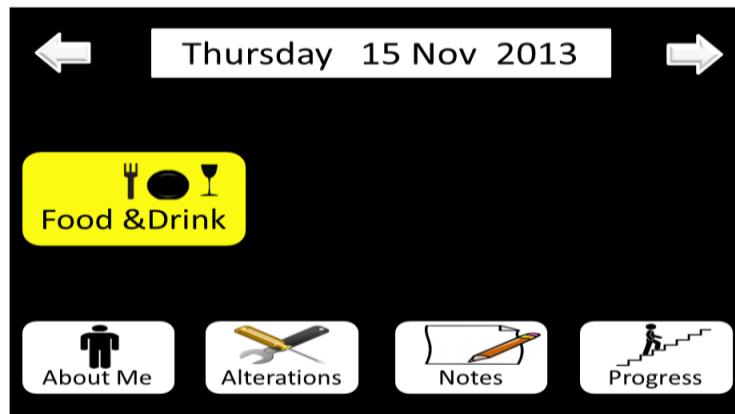


Figure 4-9: Interactive mock-up of the 'Main Menu' created by the researcher using PowerPoint.

4.5.2.1 Icon Design and Command Naming

A considerable amount of time during the PD sessions was assigned to discussion about icon designs, in particular to the advantages of their use (as opposed to reliance on words) in terms of immediate recognition (and, if necessary, recall) and increased application accessibility. Despite being unfamiliar with the whole concept of an icon and, as claimed by three participants, being unskilled in creative work, our participants were determined to design icons that were specifically accessible for their generation in contrast to those used in existing applications (as viewed on an iPad) – as a one participant noted:

“If everyone else uses such things [icons] on computers, than its best for us to use it too, so that we can learn the proper way! It would open up a light for us”.

Icon design actually proceeded hand-in-hand with decisions about the naming of the various functionalities/options within the application – comprehensibility of existing functionality-related terminology on the iPad was also considered to be poor from our participants' perspective.

It is widely recognised that UI icons are not generally intuitive but are often learned. In accord with this, because our older adults have not been computer users throughout their lives, the existing icon designs and naming conventions used within current applications were not found to be consistent with our participants' mental models based on their life experiences, familiar environments, and use of everyday objects. Consequently, such icons

served no useful purpose for them. For instance, the team vigorously debated the name for the 'Settings' and 'Tools' options on the iPad, arguing that these did not indicate to them they could alter or make changes to the screen and personalise the system. Initial alternative suggestions included 'Change my screen', but whilst participants believed it to be 'direct' they acknowledged it was 'unclear'. After much deliberation, our team decided to name the associated functionality within our application 'Alterations'. Our observations in this regard seem to be consistent with other research. For instance, a recent study (De Rouck *et al.*, 2008) found current icons for medical information systems to be inaccessible as opposed to



Figure 4-10:Participants' icon design and command naming.

being *recognisable*, *intuitive* and *easy* to identify by end users; to combat this, a participatory design process was used to design more usable icon designs. Fundamentally, as suggested by Massimi *et al.* (2007), older adults' mental models do not match how current technology works, and more research on this needs to be undertaken to assist designers of future technologies. We deliberately did not pre-suppose the icon designs that would be useful to this audience and so the icon designs that emerged from our PD sessions encapsulated key design findings that would not have been uncovered without direct involvement of our users (see Figure 4.10 for examples of participants' icon design and command naming).

4.5.2.2 Input Modalities

An important (and challenging) aspect of designing the application was identifying appropriate methods for inputting information into the application. One key example was the need to record their daily intake of food, with all participants agreeing that relying on text entry – either via touch or a stylus – to record this information would be extremely difficult for

them. After some deliberation, we decided to mirror a concept similar to the 'eat well' plate approach recommended by the Department of Health (Department of Health, 2012).

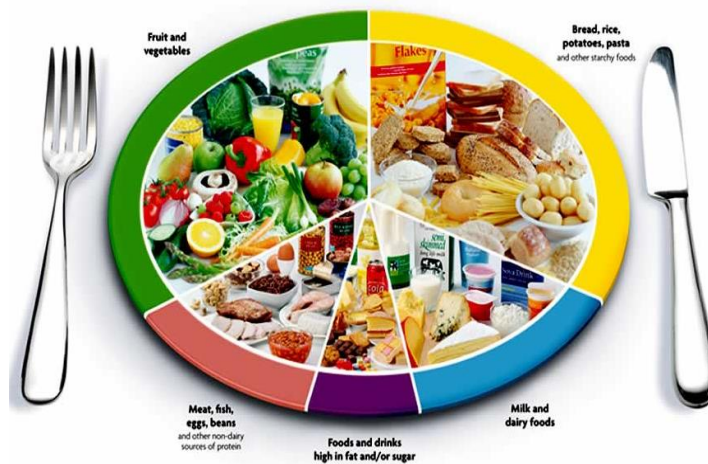


Figure 4-11: Eat-Well Plate [<http://www.dh.gov.uk/health/2012/06/about-the-eatwell-plate/>]

As illustrated in Figure 4.11, the plate provides a visual representation of the types and proportions of foods required for a well-balanced diet; in our case, based on similar visuals, users would select a food to enter by accessing the appropriate main food group and then selecting the specific food from that group. For the development of the application the type and number of food groups was altered to keep the selection process simple and to focus on detail (as opposed to higher-level food group selection) only where necessary to support specific AMD-related dietary recommendations. Participants initially raised privacy concerns and appeared reluctant to the notion of recording their diet information on which basis to then receive customised dietary advice/recommendations; a real point of concern was unauthorised access or monitoring of their data (i.e., food entries) and the fear of disapproval and being judged. For instance, they were cautious about the level of alcohol and 'fast food' consumed, or as one participant questioned:

"Will it tell me that I'm overweight?".

After a comprehensive and careful explanation of the necessity for recording their dietary intake and receiving recommendations/advice, participants were keen to learn where "*all that information*" would "*go*" (i.e., be stored), who would have access to it, and where the recommendations would come from. To reassure participants, a brief and appropriate-level

explanation about databases was provided and we demonstrated how to search for an item within a sample existing diet diary application available on an iPad.

For entering notes, participants similarly wished to avoid text-based data capture and instead expressed preference for taking pictures whenever possible. Having said that, we would always make an on-screen keyboard – for users to tap with a stylus or touch – available as an alternative for those users who are capable of using it and who prefer a more direct input method. In this regard, users were unanimous in their stated preference for the use of a stylus over finger-based touch to input text via the keypad.

4.5.2.3 Compliance – Motivational Mechanisms

As a team, we explored motivational design features such as goal setting and virtual rewards as means to encourage engagement and proper use of the application. Motivation was seen by participants as linked to progress; they saw progress as being the main purpose of the application and, as such, a motivational factor in its use. This is illustrated in their inclusion of functionality for directly checking progress (the icon for which was designed to be a person climbing up stairs – see Figure 4.9). In exploring the notion of goal setting as a motivational mechanism, we came up with the visual goal-tracking concept of an interactive bar chart representing the most important vitamins/minerals/etc. (from an AMD health perspective) that would get filled up based on users' food intake. As a virtual reward (representing a further motivational mechanism) for following their daily food recommendations and advice, participants suggested providing users with extra hints and tips, including recipes for use of their favourite AMD-beneficial fruits and vegetables.

Interestingly, one participant suggested that comparing performance with friends could also be motivational. Due to time constraints we did not incorporate a specific functional feature to support this in our prototype design (recognising that such a comparison can be, and may even be better, achieved outside of the technology itself) but plan to consider it further in future research.

Together, we believe these recommendations stand as clear evidence of the progress participants were making in terms of understanding and envisaging technology and its use as a consequence of participation in the design process.

During the final design session, participants were presented with an interactive mock-up (created by us using PowerPoint) of the final design (see example screens in Figures 4.9 and 4.12) in order to reflect on the final product of this stage of the participatory research and identify any shortcomings in the design before we commenced with developing the actual system.

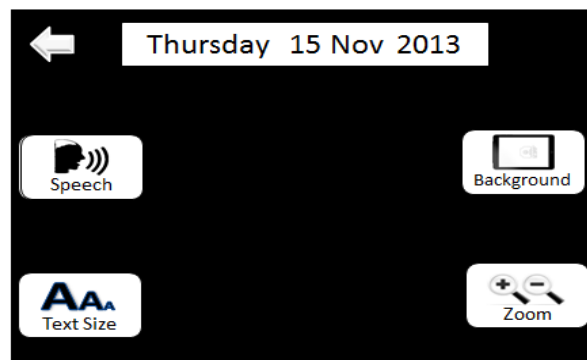


Figure 4-12: Interactive mock-up of the 'Alterations' created by the researcher using PowerPoint.

To start with, participants collectively tested the system from the perspective of 'switching' through all its provided functionality. After that, participants identified possible scenarios/tests and walked through those. Hence, it was largely the participants who drove and took ownership of the context of this stage of the process. Overall, participants were really happy with the outcome and only suggested subtle changes in terms of rewording and/or renaming options/questions. Most importantly, one participant (who was not computer literate and had more severe visual deficiencies) found scrolling to be more intuitive and stress-free than flicking or turning, explaining that:

"Scroll down is continuing, whereas for flick or turn I have to reposition my eyes. It's better if I'm keeping my head at one position, so scrolling is better".

Although this wasn't necessarily confirmed by all participants, we intended to take it into consideration during the development of the system.

As is hopefully illustrated in the above discussion about the actual design outcomes, participants were very much engaged in a reflective and reflexive process throughout the PD sessions; it was this process of reflection that allowed them to refine, further develop, and progress both their design and their level of understanding – without it, the PD process would not have succeeded. Participants were not given any ‘homework’ between sessions and, as a result, had the space to personally reflect on the previous session outcomes/challenges. It was not uncommon for participants to telephone the researcher between sessions to discuss the result of their reflection ahead of the next session. One participant recalled when contemplating the input methods for the diet diary:

“I’ve been wracking my brain about this food business; every time I start doing something [...] I think of this food page”.

4.6 Participants’ Evaluations of the PD Process

While taking part in PD sessions was a novel experience for all of our participants, the practice of conducting PICTIVE PD with older adults with AMD was also novel. From our perspective, the process was, indeed, a success in terms of (a) the tangible outcome of the sessions (i.e., the final prototype designed by the team and rich set of elicited requirements determined via the prototype and associated discussions); and (b) the extent of participants’ involvement in and contribution to the process as ‘experts’ living with their condition. Whilst we found the overall process extremely valuable and illuminating, we were also keen to assess whether our chosen method was the right choice for our target users from their perspective.

During the final PD session, we briefly reviewed participants’ thoughts on and experience of participating in the study process using a short questionnaire (see Appendix B.2). The questionnaire consisted of a combination of five closed, 5-point scale questions (with 1=lowest and 5= highest scores) and a series of open-ended questions. Since some writing was required to answer the open-ended questions, participants worked in pairs to answer those questions and the researcher helped to write the answers for one participant.

Participants' overwhelmingly positive responses (with $M = 5.0$, $SD = 0.0$) to the former are summarised in Table 4.2.

Table 4-2: Average subjective scores (out of 5, with 5 being most positive) for closed post-design questions

| Questions | Average Responses | | |
|-------------------------------------------------------------------------------|-------------------|-----------------|-----------------|
| | Focus Groups | In-Home Studies | Design Sessions |
| <i>Did you enjoy taking part in this study?</i> | 5 | 5 | 5 |
| <i>Do you feel you have been able to make a valuable input to the study?</i> | 5 | 5 | 5 |
| <i>How useful do you think each of the component parts of the study were?</i> | 5 | 5 | 5 |
| <i>How easy did you find it to participate in the various sessions?</i> | 5 | 5 | 5 |

Our aim was to ask for participants' feedback on their experiences of participating in our research study and the UCD methods used (i.e., from focus groups to design sessions), and to assess their opinion of the end design of which they had stakeholder ownership. Whilst we acknowledge that our participants' responses could be argued to demonstrate clear evidence of the Hawthorne Effect, over the course of the research, the researcher and participants had developed mutual respect and a strong bond which allowed for open and honest exchange of ideas and opinions; as such, we hope that our findings are a true reflection of respondents' feelings.

Overall, participants' feedback indicated their delight and satisfaction in taking part in all aspects of the research study; they all also demonstrated a willingness (in fact keenness) to continue with the process. As anticipated, participants were similarly pleased and proud of the resulting prototype design; one participant thought it was simply "excellent", and another one wrote:

'Others (i.e., people with AMD) will benefit from this design. I feel it is very simple to understand'.

Another participant added:

"It's going to be very useful and going to take off. There is future for it!"

When asked about the generalisability of the prototype design and general benefits of the proposed application to other people with AMD, our participants responded:

“Very much so, they will benefit from this design and I feel it is very simple to understand”.

“I have no doubt about the positive future of this project”.

“Oh my god! Yes, yes, yes, most definite”.

As already discussed, we believed that misconceptions about laboratory-based research made older adults reluctant to participate in research studies. Thus, one of our post-session questions aimed to discover whether or not participants' opinions of research studies had changed as a result of participating in our study. It transpired that, with the exception of one participant who had merely filled in a questionnaire for a research study, none of our participants had ever actually participated in a research study. As such, we were unable to compare their past experiences of being involved in a research study with our study; it would seem we did, however, succeed in changing our participants' attitudes about research studies in general. All participants selected the highest score possible to indicate their enjoyment in taking part in the study, and their ability to make a valuable contribution (both questions related to all of the knowledge elicitation methods). One participant's explanation for her rating was as follows:

“Interactive projects are exciting! Yes - I have seen first-hand the benefits of this type of research. I have felt very ‘responsible’ for the success of this project”.

Other participants added:

“I am fully in it. We should all participate”.

“The researcher was so patient, I gained a great insight into her work, she was brilliant”.

Participants unanimously expressed disappointment that it was their last meeting for the time being. As one participant summarised:

“It was challenging, thought provoking and exciting! I would happily be involved in future projects of this nature. It has been a pleasure to be involved”.

Another participant added:

“I feel and only hope that this will help others. And the way this was conducted was second to none”.

When questioned how we could improve similar studies in the future and asking for general recommendations, only one participant suggested short coffee breaks for sessions longer than 3 hours and perhaps providing drinks throughout the session, whilst others responded:

"I give [researcher] 10 out of 10, she was a joy to work with. The study was conducted in a great manner, cheerful and easy to understand, the sessions were most informative, easy to understand".

"Great! It has been a pleasure to be involved".

"I like the organisation. I like taking me to my house and picking me up. Thank you for the opportunity. Perfect!"

We concluded the final session with agreement to meet up as a group again in the future should there be a need for major design refinements or if issues needed discussion during later development phases; participants also agreed to meet up with the researcher on a one-to-one basis at their homes as required. Participants were informed that we intend to conduct a more comprehensive evaluation of both the final prototype design and their experience designing it in the near future; all were eager to continue with the process.

4.6.1 Individual Interviews

To encourage participants to comment with the benefit of hindsight, we conducted a very informal one-to-one interview with 3 of our participants (unfortunately, our fourth participant could not take part due to ill health); interviews were conducted at participants' homes at their request, and occurred 3 months after the final PD session discussed above. Each interview lasted about an hour. The main objectives of the interviews were to informally learn about participants' experiences of taking part in the PD sessions and their opinions about the manner in which the sessions were conducted (including their aim, the design space and pace of work). In particular, we hoped to determine what aspects they found interesting, valuable, confusing, challenging, etc., how similar sessions could be improved in the future, and to collect feedback on the actual prototype itself (see Appendix B.3 for sample question discussed during the meetings). All interviews were recorded and, subsequently, transcribed. All data collected was qualitative.

Overall, all participants very much enjoyed the design meetings. One participant's somewhat moving feedback aptly exemplifies and summarises all 3 participants' views on the design sessions:

"It has given me an interest in what the blindness has done to me. So from those sessions it's a bit like seeing it rise from the ashes. It brought me a life, and for that I am grateful for, and, indeed, the friends that I made. It was fun, not only was it educational, it was fun! I looked forward, so it gave me an outlook of life really. It gave me something back that losing my sight had pinched away from me!"

Other participants added:

"I really, really, enjoyed it. It was wonderful how we got on together all suffering different levels of same disease".

"When you first approached us, I wasn't sure what you really was going to ask us to do, but when we started, I thought the way you set it up was ideal. [...] And it really opened my eyes, it was just fascinating [...] It was really educational".

In terms of the meeting space, participants enjoyed traveling to the University; they found the table set-up really "useful" and appreciated the opportunity to "pass things" around. One participant suggested a smaller room with more windows could have been more suitable. All participants were astounded to learn how simple office supplies such as coloured paper, Post-It™ notes, and pens could be used to design 'technology'. All commented on their initial surprise to see those on the table, and to 'see' in subsequent meetings how those were brought together to develop and form the whole concept of the design. As one participant noted:

"It came all together so wonderful, like a good play, brilliant, good plot, excellent!"

Others explained:

"Sitting around the table was good, we all kept passing around things, so that was good, ideal place to work".

"You did so well considering you have got almost an infant a junior and secondary in one group".

Participants found the short summaries at the beginning of each session beneficial for understanding the aim of each session and felt at ease asking questions whenever necessary. Similarly, they found it 'easy' to contribute to both the discussions during the meetings and the actual paper design. This was essentially due to the group's dynamics, positive atmosphere, where everybody was interested in what others had to say, no one was

'dominant' (thus no one felt 'threatened'), and because the meetings were not tightly structured. Participants formed strong bonds, and hoped to remain friends after the completion of the project. As one participant explained:

"We were all different people, but gelled really well. I think you chose [participants] really well. [...] nobody missed a session, nobody complained; nobody got fed up of coming. We had to wake up early, wait for taxi, yet no one of us minded, we obviously all got something out of it, otherwise why would you go somewhere for 3-4 hours?"

The following reasoning from one of our participants positively substantiates our rationale for loosely structured sessions and highlights the importance of the summaries and quick updates provided to participants throughout the sessions:

"I always found it clever, because you talked about the session and the beginning of the sessions. I felt that we were on the same road together and we were trading this path and occasionally we go off the side roads and you have to go back on. But those discussions weren't wasted time discussions that happened during the break [...] I think whatever happened irrelevant or not, the sessions wouldn't have worked without it."

Another participant elucidated:

"Because you hadn't that tight structure, nobody felt threatened, I think if you had made it tight people would have felt 'oh dear can I say this [...] everybody was interested in what everybody else had to say'."

Further, because participants did not feel stressed (both during and after the meetings), and no 'homework' was involved, they actually came away from the sessions thinking about issues discussed (on two occasions, participants phoned the researcher to discuss solutions to a problem encountered during the session).

Participants commented that the activities during the design sessions stimulated their learning, and that the PICTIVE PD sessions were a good way to learn about technology. Participants were "surprised" to "learn" and "enjoy" something they previously did not understand.

Participants felt a sense of pride and ownership of the final prototype design. At one point, one of the participants was questioning the researcher's opinion on "their" design. They identified that their opinions were taken on board and manifested in the final design.

Completing the design sessions was a major achievement for all participants; they felt privileged to have been asked to participate. One participant explained:

“All my children were very impressed. I was baffling with science! You have asked me to do this, because you can clearly see something in me that the project could benefit from, I felt very privileged, really!”

All participants expressed disappointment that the design sessions drew to a close and, remarkably, could not really offer any significant suggestions for improvements. They would have been happy to have continued with the process. They were all anxious to see *“their”* prototype implemented and put to practical use. In discussion, repeated reference to *“their”* design demonstrated the level of investment in and ownership they felt for the design.

Overall, participants’ post-process feedback emphasised that participating in the project had heightened their perceptions of independence; they felt that they were effectively contributing to society (and their community) by being able to apply *“unrelated”* skills (essentially their wealth of experience and knowledge) to the development of an assistive technology from which future generations could benefit. In general, themes of *mutual learning*, *socialisation* and *empowerment* emerged strongly from the feedback process (these are further discussed in Chapter 5). As such, we consider the process to have been a success – both methodologically for both parties, and in terms of the design output it generated.

4.7 Validation of the Prototype Design

Following the interviews, the researcher attended a local community support group for people with AMD -to validate the prototype design with volunteers who had not previously been involved in any phase of the project. The aim of this phase was to validate the prototype design in terms of its generalisability (i.e., intuitive command and option naming, icon design and placement of the user interface components) across more members of the intended user group. As per practice reported in Chapter 3, at the start of the support group meeting, the researcher was invited to give an informal presentation (10 – 15 minutes long) about the aims and objectives this phase of the study before staying for the remainder of the meeting to enable interested individuals to take part in the validation activity. 6 people with AMD

volunteered to take part in the study (but no other demographic information was collected about the participants). A PowerPoint mock-up of the paper prototype design was shown on a laptop, but participants had also the opportunity to ‘see’ and ‘experiment’ with a Samsung tablet to help them envision how the diet diary application could ‘work’ on a tablet device. To start with, the researcher conducted a walkthrough of the higher-fidelity version of the prototype design (and its functionality), after which participants had the opportunity to ‘play’ with the prototype, and were asked to provide their informal, formative feedback on the prototype – all participants were seen individually.

Three out of the 6 participants who volunteered said they would use the application. The other 3 were more reluctant to accept the concept of a dietary application per se, the underlying reason being scepticism that nutrition could have any positive influence on their eyesight at their later stage (70+) of life. Interestingly, our design participants also recognised that the application was probably of little direct value to them given their stage of AMD progression, but were keen to identify means by which to help future generations avoid the vision loss they had endured.

Other than this, all 6 found the command/option naming and the design and use of icons to be “*clear*”, “*self-explanatory*” and “*straight-to-the-point*”. One participant explained that the “*clever*” design/ and use of the icons would eliminate the need to read labels and, as such, make the interaction more “*enjoyable*”. Furthermore, all agreed that the placement of the interface components was suitable, and offered no alternative arrangements. Participants did not actually comment on the hardware choice, but agreed that they would use similar devices as long as they could see the interface and its components.

4.8 Discussion

By directly integrating participation of older adults with visual impairments (i.e., AMD) in the design process for assistive technology to support their needs, we (as designers of such technologies) anticipated establishing a deeper and more valid understanding of our users’

needs. We also anticipated that this inclusive process would contribute to and influence the ultimate success of the technological development in terms of technology acceptance (including increased confidence in the use of technology) and ultimate impact (both in terms of improving peoples' lives and affecting future technology design) – see Chapter 7 for discussion in this regard following a field study of the technology use.

A major challenge identified in terms of the user interface design was the placement of the components such that the resulting technology could be used effectively and independently by persons with AMD. This required the atypical placement of the UI components around the edges, leaving the centre clear. Furthermore, the UI layout needed to be adjustable for a given individual based on auto-observed degeneration of visual acuity over time.

A further challenge included finding appropriate methods for inputting information into the application. As noted, participants found inputting information rather challenging and, although a mechanism similar to the proposed 'Eat Well' plate concept was identified as hopefully supporting the elimination of the need for 'typing', it was recognised that it would still require substantial visual attention in terms of reading available options (a challenge that would need to be supported effectively given the needs of our users). An important consideration for our application deployment was its success at affecting behaviour change and the design activities usefully highlighted participants' preferences for the practical motivational aspects associated with such change – e.g., participants preferred charts and graphs for feedback purposes, and all agreed that beneficial feedback would motivate them to adhere to the dietary advice and recommendations. As already mentioned, one participant suggested that comparing performance with close friends would also be motivational; while we would hope to examine and evaluate this in the future, it was felt this was outside the scope of our current research as it would essentially expand the focus of the proposed application from a user-based tool to a more 'social' tool. In so doing, it would likely raise privacy and security issues associated with such functionality provision, and require further close collaboration with users to investigate this concept.

Our experience, combined with our participants' feedback, indicates that our tailored PICTIVE PD method was a valuable tool for involving users with AMD in design activities, and for encouraging them to act as fully empowered co-designers, thus encouraging creative design thinking and inclusive participant contribution, regardless of level of visual impairment and computer literacy. While the primary outcome of our PD sessions was the specification of the UI for our diet diary application in paper prototype form (see Figures 4.6a-d for an illustration of how the paper prototypes evolved during the process), results from our participatory work suggest that our involvement of participants drastically altered, in a positive way, their opinion of research and their ability to contribute in a meaningful way to research. On the basis of our experience, we have derived recommendations for involving older adults with impairments in participatory design activities, and document these in Chapter 5.

4.9 Study Limitations

Although highlighting the benefits of following a participatory research approach, both in terms of the prototype design and older adults' contribution to and benefits from being involved in the design and development of technology, this phase of our research was not without its limitations. The study has been conducted with a small sample of hand-selected users which, it could be argued, may have influenced the results in terms of our participants' reported satisfaction and perceived benefits of taking part in the PD activities – rendering results that would not be generalisable to the AMD population at large. Findings, however, from the preliminary evaluation study validate the prototype design in terms of its generalisability across more members of the AMD community. Furthermore, as already noted, we believe (and findings from our evaluation studies (discussed in Chapter 7) corroborate this) that for a participatory design team to work well, rapport with the researcher, interpersonal engagement, commitment to cause, and participants' comfort in interacting (as a consequence of growing interpersonal bonds) with each other are essential; these pre-requisites would not be as attainable with a random and larger group of

participants, and are only possible to achieve with the ongoing involvement of an increasingly engaged cohort.

Whilst it could be further argued that our lack of inclusion of individuals with early onset AMD might have led to skewed design objectives, we posit that the involvement of participants with advanced AMD enabled us to design the user interface such that it (a) can cope with worst case scenarios and therefore be used effectively and independently by persons with more advanced AMD which would not be the case if we had focussed on people with early onset AMD, and (b) will be adaptable to different levels of visual impairment over time, starting from the default layout of the UI which will be for nearer normal vision (and for which we did not necessarily require specialist input).

4.10 Summary

The result of this study, in tangible form, was that a clear prototype design for our proposed diet diary application together with a rich set of elicited user- and software-related requirements was derived that we were confident represents the needs and preferences of our target users.

In terms of the methodological approach, the PICTIVE PD method proved to be a natural fit with the identified capabilities of our target end users and the objectives of the design activities. The method is ideally suited to working with small groups – a bonus when working with special needs populations where identification and recruitment can be problematic. With hindsight, without the benefit of such close involvement of members of our user group throughout our research to date, we would not have been able to relate to the specific problems, preferences and coping strategies of our target users. It was only through the ongoing direct involvement of our target users that we were able to effectively assess their needs and expectations and design our proposed diet diary application to meet their needs.

Finally, the method lends itself very well to adaptation relative to the specific needs of individual participants (or groups with diverse needs), discussion of which is documented in the next chapter together with a discussion of the dominant themes emerging from thematic analysis of the records of our participatory design activities, and preliminary evaluation of the PD process with our participants.

Chapter 5. Reflection on Participatory Design for and with Older Adults with AMD

5.1 Introduction

The discussion in the previous chapter has substantiated the advantages of involving older adults with special needs in PD activities, in particular in terms of the tangible outcomes of the process (i.e., a paper prototype design that should be effective for and acceptable to the target user group). Nonetheless, it is anticipated that some developers may be wary of engaging with PD activities with individuals with special needs on account of the perceived complexities associated with accommodating their needs in order to include them in the process. In the hope of assuaging such potential concerns, and in trying to demonstrate the positivity of experience that arises out of engaging in PD with special needs users, this chapter reflects on our *experience* of adopting and adapting the PICTIVE participatory design approach to support effective design with and for our special needs user group. We reflect on participants' views of being part of the process, discuss the design themes emerging from our PD activities, and suggest recommendations for (or further insight into) how direct

involvement of special needs users might be successfully achieved with relatively easy adaptation and/or accommodation of standard design practices. We present a series of themes and guidelines that have materialised from two sources – our reflections and exploration of the participatory design process, and the feedback and reflections from our participants.

5.2 Emergent Themes

As previously noted, application of the PICTIVE PD method was a reflective and educational experience for all parties involved. The video-recordings from the sessions themselves were transcribed and returned a rich set of data from which some distinct themes emerged as result of in-depth thematic analysis. Table 5.1 outlines the six phases of the thematic analysis process which were followed to analyse the study data.

Table 5-1: 6 phases of thematic analysis (Braun and Clarke, 2006, p. 87).

| Phase | Description of the process |
|-------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. Familiarising yourself with your data: | Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas. |
| 2. Generating initial codes: | Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code. |
| 3. Searching for themes: | Collating codes into potential themes, gathering all data relevant to each potential theme. |
| 4. Reviewing themes: | Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis. |
| 5. Defining and naming themes: | Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme. |
| 6. Producing the report: | The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis. |

To conduct the thematic analysis we first familiarised ourselves with the data by carefully reading the transcripts. Following this, a second reading was conducted to summarise preliminary topics that identified important features within short segments of data. Individual data extracts were then labelled or coded with a descriptive word or phrase summarising key

points. These codes/labels were then sorted and combined into coherent groups that identified broader patterns of meaning.

It should be noted that individual data extracts were at times associated with multiple codes, yet individual codes were reapplied to different data extracts only when the conveyed message of both extracts were almost identical. The potential themes were identified by sorting and combining relevant codes (see Table 5.2 for an example of how codes were applied to data extracts from the PD transcripts).

Table 5-2: *Examples of data extracts with codes applied.*

| Data Extracts | Coded As |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------|
| It's a brilliant idea, because if we, and the likes of us, can learn it, you know, it's marvellous, it keeps your brain active, it stimulates its cells. You might do it for keeping track of food but it will also keep your brain cells alive. | <ol style="list-style-type: none"> 1. Stimulates learning 2. Keeps brain active |
| The idea that I can be on computer – I would love it! It would make me feel intelligent again, it's so embarrassing with this condition so I don't go out and this would be wonderful. And now that my daughter goes to university, I can go on Facebook and keep in touch that way. | <ol style="list-style-type: none"> 1. Improves self-esteem 2. Prospect of being connected/keeping in touch |
| We could enter our name, so when you switch it on it says: "Good Morning [name]". This way it's more personal, it's a motivational thing. I would think then at least someone is thinking about me. It makes me feel happy, it sounds nice! | <ol style="list-style-type: none"> 1. Importance of personalising 2. Motivational factor 3. Combatting loneliness/isolation |

Following this, the themes were reviewed to ensure their validity in relation to the coded extracts and to the entire data set. Finally, informative names for each theme were generated by analysing the key aspects each theme captured. During the entire process attention was paid to the original transcript to ensure that the developing themes were representative of the participant's accounts. Figure 5.2 provides an illustrative example of the final stage thematic map of initial themes and sub-themes/codes (codes and themes are embedded in rounded rectangle and oval shapes, respectively) demonstrating how different data codes are allied and how they at times simultaneously correspond to several themes (e.g., the data code 'Praise and encouragement' fits both into the 'Mutual Learning' and 'Empowerment' themes).

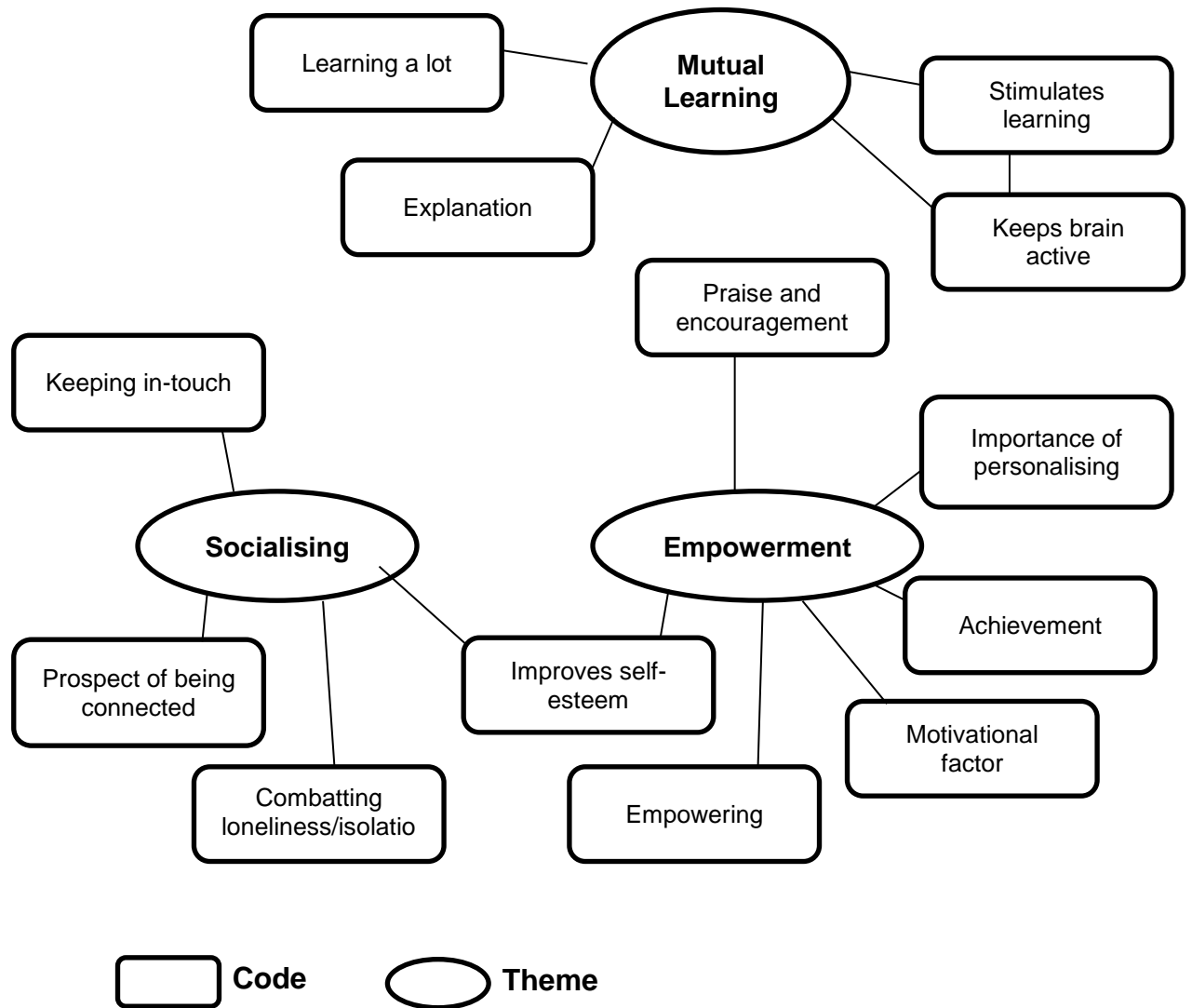


Figure 5-1: Initial thematic map of emergent themes and codes

5.2.1 Mutual Learning

The dominant theme to emerge from our activities was the mutual educational nature of the process. Our objective for adopting UCD – and, in particular, participatory design – approaches was to learn about the needs of users with AMD, to appreciate the implications of designing for this user group and to understand how these implications can encourage (or hinder) technology use. Despite their personal challenges, our participants invested considerable time and effort in learning new skills as part of their engagement in our research. Equally importantly, they taught us a great deal about their needs, experiences and expectations. In addition to the exchange of knowledge between the participants and the researcher, participants taught each other and delighted in each other's progress.

Participants agreed to go to each other's houses and support one another in using computers/tablet PCs:

"So when everyone has it [computer and/or tablet PC], and we have a problem, we could go to each other houses to help".

In fact, two participants were considering purchasing tablets similar to the ones they tested during the PD sessions, as one participant explained:

"my outlook has changed from being sitting here at home now I have my foot in the door here, you know, as soon as I start learning, I am going to buy an iPad, you know. You will teach me how to use it?"

One also agreed to help another participant 'operate' her mobile phone and socialise more (a subtheme discussed below).

The office supplies used within the PICTIVE method eased the process of learning about technology. Participants commented that :

"This method was great! I was picking up young [researcher's] brain, I wouldn't have been interested otherwise" and

"Coming from nothing, then enjoying something I did not understand earlier, to yearn for some more, then that speaks for itself!".

The extent of the progress participants had made regarding learning technology since participating in the project was illustrated when one of the least computer literate participants (P3 – see Table 4.1) suggested the team 'ask Google' when they failed to find a suitable name for a command.

Throughout the process, participants were keen to learn as much as possible, including pushing themselves to understand concepts that were not a necessity for successful participation in the process. An excellent example of this curiosity arose when participants asked for a comprehensive explanation of processes surrounding recording their dietary intake and receiving recommendations/advice: as previously noted, participants were keen to learn where *"all that information"* would *"go"* (i.e., be stored), who would have access to it, and where the recommendations would come from. A brief and appropriate-level explanation about databases was provided to the participants, and we demonstrated how to search for

an item within a sample existing diet diary application available on an iPad. One participant commented:

“I am learning a lot from this program. It’s like doing ‘A’ levels”.

Another participant further elaborated:

“bear in mind that I’m computer illiterate and I have been blind for 12 years now, it taught me soo much, and I am very eager to begin any session to learn [...] I really miss the sessions now [...] it [the sessions] brought to me that there is hope for me in these kind of sessions regarding to learn how to use computers even if it’s minimum”.

In addition to learning about technology, participants were concerned about the current/existing lack of nutritional guidance and appropriate support available to people with AMD. From the PD sessions, participants also learned a great deal about ‘healthy lifestyle’. During the individual interviews following the PD sessions, two participants declared that they had improved their diet since taking part in the project. This is a fantastic example of behavioural change as a side-effect of design participation alone:

“I have started to eat healthier, and I think oh how could I put it on the computer?”

Finally, as already mentioned, we learned a great deal about the IT-related needs, attitudes and perceptions of users with AMD, and older adults in general. Mutual learning throughout all stages was fundamental for the endurance and success of the project; we were reassured by participants’ willingness to learn from and contribute to the PD sessions. Their positive interaction with computers (for those participants who owned computers) and reflections of their involvement demonstrated that older adults (with AMD) could and would use technology and participate in research studies of a similar kind if the potential benefits of such commitment (both in terms of technology use and research participation) are easily understood and appreciated. One participant summarised her experience as follows:

“Pat on my back. I helped to design it [the diet app]. It’s an achievement. Very good. I think it boosts your ego. Because people of my age don’t have an opportunity to go to university and learn new things, and be part of something like this”.

5.2.2 Socialisation

By being involved in the project, participants also gained an opportunity for socialising (a valuable component in the general wellbeing of the elderly, especially elderly who are often

otherwise isolated as a consequence of disability such as AMD, which can be a very isolating disease (Stanford *et al.*, 2009; Wong *et al.*, 2004a)). Our participants spoke very highly of their involvement – for example:

“It’s like when you hear a story you are engrossed in it, so I became engrossed in it [design sessions], [...] I did not want to come away from it”.

Since all members of our PD team were involved in all of our preceding UCD methods, a very strong bond formed between the participants and between the participants and the researcher. Since the sessions were not tightly structured, there was opportunity for participants to occasionally engage in social conversation, as one participant noted:

“The amount of time we spent together, you know we did not know each other, so it was all about what we were doing in the sessions. It was natural [...] it was like social gathering, very friendly”.

Other participants explained:

“We enjoyed going out, it was like a day out and an enjoyable day out”.

“It’s the dynamic. We never met, except for coffee, so in between what we were doing, we were actually getting to know each other, and that actually helped to trust each other more, and to work on the project”.

Although these tangential benefits certainly resulted in slow progress at times, this proved necessary to encourage and motivate participants, as exemplified by the following quote:

“I think if it would have been faster, it would have restricted our thinking, because we were walking on new ground [...] if it had gone any faster, maybe one of us would have been left behind”.

Interestingly, whenever the conversation deviated onto a social topic for too long, one of the participants (as opposed to the researcher) was always first to prompt the team to return to the task and keep working!

Additionally, after every PD session, the team (including the researcher) went to the University’s coffee shop for a hot drink with snacks. This presented a great opportunity for participants to discuss matters outside the project scope (i.e., family, health, travel, etc.) and further cement their friendships, including that with the researcher. Participants’ post-process feedback emphasised the importance of their bond with all team members; they considered this friendship as a key factor in their motivation. One participant reflected:

“I feel now I know all of you really well, but I don’t know you that long, so something happened. [...] I felt that whatever you said I came away thinking about it. That was as a result of the atmosphere that you had created in the group [...] It was a pleasure to work with all the lovely ladies [...] it was something that all of us enjoyed”.

It is worth noting that, on no occasion did any of the participants reschedule, cancel or miss a PD session, with the exception of one member who was unable to attend the last meeting due to ill health. One participant, who was very keen to participate in the project but was initially sceptical about working with others in a team, made the following comment:

“After 12 years, I have met people, and made good, firm friends [...], I was encouraged to speak and say what I felt [...], I really miss the sessions now, it had brought a hope for me!”.

Finally, participants indicated that they could better relate to and feel part of a much younger and technologically-advanced generation (reinforced by the researcher’s age and profession) as a result of being part of the process. We believe this relationship was the fundamental source of motivation and determination for participants to *“try their best”* – as one participant encouraged others during one of the design sessions:

“None of us want to let [researcher] down, so when we start this we will keep on going, we got to prove it. We are the pioneers”.

5.2.3 Empowerment

As already noted, by adopting a PICTIVE PD method we hoped to empower older adults with AMD – to make them feel relaxed and able to contribute to the design work without prior technical knowledge or expertise. This was an inspiring and encouraging experience for our participants, who were proud of being part of a research team. In fact, to them this enhanced their social status. For instance, one participant proudly explained:

“My building’s manager was very impressed; she had someone in her complex who was going to the university”.

Another participant was extremely honoured and delighted when she was asked to report on her research involvement with Aston University for a local magazine after sharing her continued enjoyment and appreciation for being asked to participate in the study with members of her local community support group. In the magazine she explains:

“It has been really interesting and I’ve enjoyed being involved. The work is very impressive and although it won’t help me, hopefully it will benefit future generations.” (Stokes and Bishop, 2013, pg. 9).

This experience changed our participants' outlook of life, stimulating strong desire to aim higher at this stage in their lives. Two participants expressed regrets regarding not obtaining university degrees, and mentioned that they would have considered an Open University degree if they had met the researcher some years ago.

Participants spoke highly of their involvement and the prototype design:

"It was a unique experience, I am most grateful for it. [...] I am very proud that someone could benefit from it".

For three of the participants, taking part in the project was a unique opportunity to contribute to and influence something important/beneficial and, as such, take charge of their lives since losing their sight.

5.3 Participatory Design Recommendations (or Considerations)

In general, our PD approach proved successful at encouraging creative design thinking and inclusive participant contribution, regardless of level of visual impairment and computer literacy. That said, due accommodations had to be given to the way in which the sessions were conducted to account for (a) participants' individual impairments, and (b) the fact that this was a novel experience for the participants who were trusting us in terms of being with us in our arena rather than in their own comfort zones (in contrast to our knowledge elicitation phase during which we engaged with participants in their domain). Generalisations of the adaptations or methodological concessions we accommodated are outlined below.

The choice of the PICTIVE PD approach seemed a natural fit with the identified capabilities of our target end users and the objectives of the design activities. Furthermore, as is outlined below, the method lends itself very well to adaptation relative to the specific needs of individual participants. The method is also ideally suited to working with small groups – a bonus when working with special needs populations where identification and recruitment can be problematic.

5.3.1 Recommendation #1: Adapt Your Selected Method/Approach for the Specific User Group Requirements

Although our PICTIVE PD sessions were loosely structured – to place participants in charge – we accommodated adaptations or methodological concessions (based on participants' impairments) to enable our participants to fully participate in and contribute directly, in an empowered way, to the design sessions. Furthermore, we encouraged our participants to dictate the length of time they were willing to commit to each session, affording them additional procedural control; consequently, the sessions typically overran initial timeline estimates at the request of the participants. Interestingly, this is in contrast to suggestions arising from previous studies with special needs users, that recommend sessions be more structured and run for under 2 hours (e.g., Lindsay *et al.*, 2012b), but we firmly believe, based on our experience, that sessions that allow time for socialising and place participants in control lead to more productive group meetings and outcomes. We also noted that attending sessions at the University was similar, for our participants, to planning a day out and so they found it acceptable and positive to commit to sessions for longer periods of time. That said, we had to ensure that the sessions were enjoyable so that participants took pleasure in being with us and engaged for 3-4 hours: the following quote from one of our participants aptly substantiates our rationale and observations:

“You did not go any further, until we said that we understood. You did not rush it. You were there sometimes for 3 hours on a topic. [...] And yet we never noticed it, time just flew. You made it so interesting and got us involved. [...] I thoroughly enjoyed the whole process. I used to look forward to going to [design sessions]”.

We eliminated the need for participants to read/write during the sessions; drawing and writing were, to a large extent, the researcher's undertakings with some assistance from one participant who had very early stage AMD and was rather artistic. We realised very early on in the design process that, to accommodate our participants' visual deficiencies, they would benefit from their own copy of the paper prototype in addition to the one shared at the centre of the work space (for an example see Figure 5.1). Although this accommodation deviates slightly from the core tenet of PICTIVE PD (that is, the development of only a single, shared copy of a prototype), participants truly appreciated this mode of working because it allowed each individual to position the copy at her preferred viewing distance and angle, something

which they were not comfortable doing with the large, centralised copy. This also supported personal reflection on the ongoing progress of the design.



Figure 5-2: Shared work space showing individual copies of the prototype at the sides in addition to the shared (enlarged) copy in the middle.

One-to-one explanations and demonstrations were a prominent part of the sessions; once something was drawn/sketched (i.e., a user interface component) on the shared material, this was passed around the table for participants to be able to see. We had considered the use of a white/blackboard for demonstration purposes but refrained from using one as we feared this would draw attention to their visual deficiencies rather than assist (the use of whiteboard would not allow our participants to hold it close to be able to read as per their practice for reading papers) . Similarly, we refrained from the use of paper agendas; instead, at the start of each meeting, when we conducted a verbal review of the previous session we also discussed the suggested purpose and objectives for the current session and participants were given freedom to reflexively change the agenda during such discussion. At the end of each session, participants' individual copies of prototypes were collected, refined based on the outcomes of the session as documented via the central copy, and returned, updated, to them in the following session.

5.3.2 Recommendation #2: Accommodate Comorbidity Issues

In addition to their visual deficiencies, people with AMD often have other age-related impairments, which can lead to frustration and low self-esteem (e.g., Chen, 1994) and in turn, if insufficiently considered, negatively impact their participation and contribution to design work. To encourage participants' involvement and maximise their contribution to the

design work, we needed to not only compensate for visual deficiencies but to also accommodate comorbidity issues. Our participants experienced difficulties with hearing, memory, and one participant also had arthritis. To combat memory problems, for instance, (a) each session commenced with a summary of the previous session and (b) we included quick updates (i.e., how far we were in the process and what we had achieved so far) throughout each session to recap the group's achievements. As per the practice adopted by Wu *et al.* (2004) when working with individuals with amnesia, when reviewing work from a past session, individual contributions to the design and decision-making process were not identified in an attempt to evaluate past decisions in an unbiased way and reflect the *group's* work as a collective (as opposed to the contribution of individuals).

It is also likely that most older adults will have issues with hearing, as age is the single prevalent cause of hearing loss with just under 72% of over 70 year olds reported as suffering from some form of hearing loss (Action on Hearing Loss, 2011). To combat hearing problems, we minimised crosstalk by referring to participants by their names when asking questions such that only one person spoke at a time. This was also of crucial importance to two of the participants who found conversations that are led or directed via eye contact rather challenging. As already noted, our smaller group size was also ideally suited to encouraging interaction at a level manageable to our users, in particular in terms of accommodating their hearing deficiencies. Additionally, an important consideration is also the location where sessions take place, since noise and distractions can further impede communication flow, and thus adversely influence older adults' contributions to the design work.

5.3.3 Recommendation #3: Preserve Procedural Flexibility to Speed up or down the Process as Deemed Essential

As already noted, since the PD sessions were not strictly structured, there was opportunity for participants to occasionally engage in social conversation. Although these practices certainly resulted in slow progress at times, this proved necessary to encourage and motivate participants. At times, it was somewhat challenging for our participants to retain

focus, learned concepts and skills. It is, therefore, important to preserve flexibility in terms of the pace at which the sessions are conducted; to be able to speed up or down the progress, in order to enable older adults (with impairments) to ask questions, to repeat and remember concepts and skills whenever necessary. For some sessions, the researcher focused more on helping participants to understand unfamiliar concepts than perhaps 'prototype', but this was deemed essential for maximising their involvement and input for subsequent meetings (see Section 5.3.4). Further, since the sessions did not follow a strict agenda, participants who required more help (and time) to contribute to the session, felt more comfortable with discussing their issues and seeking help with understanding what was required from them (to contribute to the sessions more effectively). Whenever necessary, however, participants were similarly keen to "get on" with a given task at a much faster speed to compensate for the time used on socialising, for instance.

This also accords with ideas of Massimi *et al.* (2007), who also found that older adults required more time during their PD sessions. Interestingly, however, he also suggested that some participants felt they proceeded too slowly through the design process. This combination of findings provides some support for the recommended premise that pace - at which the sessions are conducted - is of crucial importance to older adults (with impairments), as exemplified by the following quote:

"I think if it would have been faster, it would have restricted our thinking, because we were walking on new ground [...] if it had gone any faster, maybe one of us would have been left behind".

5.3.4 Recommendation #4: Use Metaphors and Pertinent Tangible Objects to Encourage and Support Envisioning of Technology

One of the key challenges for our participants in engaging in this design work was to envisage (mobile) assistive technologies for the purpose of designing the user interface and determining functional requirements of the application, and thus maximising their involvement and input. A good starting point was a discussion of the advantages of mobile technologies concerning the portability and anytime/anywhere access of such devices. We found the use of metaphors and pertinent tangible objects of crucial importance in assisting

participants to envisage mobile assistive technologies, visualise their design ideas, and encourage creative thinking. For instance, when explaining to participants the difference between a device and its applications, how a device could run various types of applications, and that our proposed diet diary application was one such example, the metaphor of a library with lots of books was used to illustrate the function of a device with multiple applications.

To introduce an element of tangibility to the design conceptualisation, participants were afforded the opportunity to try out and reflect on related applications on an iPad (bearing in mind that we had already limited the hardware choice to tablets on the basis of focus group discussion) to help them comprehend how touchscreen technology works, what buttons are and how to navigate from one screen to another (this allowed for deeper consideration than was covered in the focus groups where discussion remained at the level of participants' overall experience of interacting with a mobile device). The iPad was passed around and, in addition to the group discussion, one-to-one explanation about the technology was provided to two participants who had never used a computer before.

5.3.5 Recommendation #5: Use Non-Technical (Accessible) Language and Provide Ample Explanations to Avoid Mismatched Expectations

We focussed on trying to understand participants' perceptions and expectations of not only our proposed application (in terms of eliciting functional requirements), but also of the overall project to avoid any mismatched expectations. We explained to participants: how our design sessions allied with the overall scope of the project – that this was the design phase of the project and that their contributions to the succeeding development and evaluation phases would also be appreciated/needed; what the subsequent stages would be – i.e., preliminary evaluations of the prototype, development of the back-end (i.e., the computational engine), followed by longitudinal field evaluations; and what the overall expected outcome was from the current design phase – i.e., a paper prototype of the UI. We felt this to be essential to mitigate against misunderstandings as a result of mix-matched expectations. For one of the

sessions the group was joined by a clinical researcher (optometrist) who contributed to the collaborative design exercise. In addition, she provided general feedback on the design created up to that point, she reviewed the application not just as a diet diary application but also as a low vision tool in general to reiterate how the design sessions allied with the overall goals of the project, and she discussed how the design findings thus far might usefully be applied more generally for designing with and for older adults with impairments. Although participants asked her various questions about the connection between different health conditions, AMD and nutrition, they were equally keen to explain to her, and thereafter evaluate with her, their design choices.

Throughout the process, the use of accessible, non-technical language by the researcher was of crucial importance when providing explanations and guiding discussions. Simple explanations that reflected participants' mental models (combined with the ability to experiment on touchscreen phones and tablets) allowed participants to effectively understand unfamiliar concepts and enhance their contribution. For instance, participants found the whole idea of navigation from one screen to another via touch/click incomprehensible to begin with. We explained it with a comparison to a book and its content page: we illustrated with a book how the content page could be viewed as a 'menu' structure from which buttons/options link to particular 'pages' of the application – similar to how chapter names (with corresponding page numbers) in the content page of a book support look-up of the corresponding book sections – noting that on a device a touch/click would take the 'reader' to the actual page as opposed to having to physically turn pages of a book. Following this, the same concept was illustrated on paper with Post-It™ notes as buttons, with the advantage that this medium of explanation (unlike the actual technology itself) allowed participants to 'see' all pages laid out in front of them and 'envisage' how 'touch' can change screens. Participants were frequently reminded that they should ask questions for further explanation whenever necessary.

5.3.6 Recommendation #6: Establish a Friendly Atmosphere

Taking part in design work is likely to be a new and, perhaps, initially overwhelming task for older adults. We found that establishing a friendly atmosphere helped stimulate and encourage individuals' contributions (other studies with older adults (e.g., Ellis and Kurniawan, 2000) have also recognised friendship between the members of the design team of fundamental importance). One participant explained:

"I loved exchanging ideas with these people, it's like playing ping pong, that's what I loved doing. I loved talking about ideas. I just enjoyed all of it".

Displaying empathy, understanding and appreciation of participants' challenges, needs and viewpoints is also of crucial importance for establishing a friendly atmosphere, where all members of the team feel equally valued and respected. A simple illustration of such an approach is for the researcher to be cognisant of the main challenges older adults face when using technology, and share with participants similar encounters of when the researcher had faced challenges with using technology. We found this reassured our participants that potential issues with using technology are applicable to people of all age groups and not just older adults (with AMD); we feel this encouraged our participants to express their views and opinions candidly and sincerely. Besides the researcher's direct rapport and identification with participants, the overall research study design and space has the potential to contribute to the suggested communication of empathy and reverence for establishing a friendly atmosphere. For instance, although our design sessions took place in a room easily accessible via the University's main lift, for every session the researcher greeted participants upon arrival and escorted them between the sessions and the taxi stand (in both directions). While participants truly appreciated this and expressed gratitude for the compassion displayed, it afforded a great opportunity for both the researcher and the participants to interconnect and engage in social conversation before commencing with the design work or after finishing with the design work for the day. Escorting participants also ensured that they did not get lost or experience any difficulties in finding the meeting room, and thus avoided any distress or anxiety. Overall, we developed a trusted and professional relationship between the researcher and our participants, which we feel was a strong contributing factor to participants' motivation and determination to *"try their best"*. This was also made possible

by the pre-PD knowledge elicitation phases already discussed that certainly contributed to the establishment of friendly atmosphere right from the onset of the project.

5.4 Summary

Like those who have used participatory design for other assistive technology design, we firmly believe that the method can be a valuable tool (if adapted to the needs of a given project) for design activities involving users from different backgrounds with different impairments (not just people with AMD) by empowering them to fully participate in the design of a technology that will impact their lives.

As already noted, our successful collaboration with AMD participants for design activities was made possible by the pre-PD knowledge elicitation activities that served to establish a strong sense of pre-existing shared interests and responsibilities among all members of the design team. This observation seems to be consistent with other research which found that participants from the same communities or pre-existing groups work more effectively as a team (e.g., Ellis and Kurniawan, 2000; Wu *et al.*, 2004), and that lack of shared interests and responsibilities among individuals can cause frustration among design team members and thus hinder the design process (Massimi *et al.*, 2007). In contrast to findings from Massimi *et al.* (2007) concerning possible conflict between three different perspectives on design – design for me, us, or them – when engaging in participatory design, we found no evidence of such conflict which might have led to skewed design objectives. Our participants' were tasked with designing for the general members of the AMD community and for those users who were at risk of developing AMD. They acknowledged that this covered a wide spectrum of users with various needs and abilities, but also recognised that the resulting UI design had to cope with worst case scenarios to be used effectively and independently by persons with more advanced AMD, whilst presenting a default UI layout that would be suitable for users with nearer normal vision.

The identified emergent themes of *mutual learning*, *socialisation* and *empowerment* also suggest that the process was a success – both methodologically for both parties, and in terms of the design output it generated. The recommendations offered in Section 5.3 are not rigorously tested guidelines but are rather considerations based on our observations and participants’ feedback. From an ethical perspective, our experience and participants’ reflections suggest that we have been successful in removing barriers to participation, adopting our research methods to suit the needs and abilities of our participants, including individuals in research that has the potential to impact them directly, and in achieving beneficence – both in terms of the deliverable and the wellbeing-related bi-products of participation (which is also supported via ongoing research activities and contact with the participants as discussed in Chapter 7).

Findings reported in this chapter, should, hopefully, provide some support for the conceptual premise that the adoption of PD method in the design and development of (assistive) technologies can actively establish and empower older adults (with impairments) as co-designers in the process. An Important issue for future research, however, is to investigate how objectives and expertise of various stakeholders involved in the design process may pull the design in different directions; and how best to manage this pull from different directions. If not managed properly, this may give rise to conflicts, particularly when attempting to build atypically-designed applications (as in our case) with designer/researcher with technical expertise, versus novice users of technology but experts with their condition, versus the demands of technology development platforms (as discussed in Chapter 6). Balancing these dynamics is of crucial importance for developing values and ideas in participatory design, such that designers are not reluctant to achieve an aesthetically ‘unusual’ design (based on target users’ needs and capabilities), and that the practicality of delivering a working system does not ebb away control placed in the hands of the users during the design. As Marti and Bannon (2009, p.14) state, “users need to be prepared for playing their role effectively, for contributing with their domain knowledge to the project, for defining concepts, for evaluating

and comparing solutions and identifying usage problems according to their abilities and possibilities to participate in the design process.”

In recent years, there has been an increased amount of literature on the application of participatory research, but accounts have tended to overlook the implications of when these participatory projects end: When does the project ‘end’ for participants? How should researchers determine when to terminate participants’ engagement? How should this ‘termination’ be achieved ethically? What are the potential implications for participants? Far too little attention has been paid to the ‘end’ process of participatory research, and it is a challenge that we acknowledge will take careful consideration (see Chapter 8).

We certainly have evidence of the positive influence participation has had on our participants thus far, and the strong bonds that have formed between the researcher and participants. Cognisant of the potential negative effect that withdrawal of the participatory process may have on individuals, we consulted them directly (via our evaluation studies discussed in Chapter 7) on how to bring closure to the process in as positive a way as possible; in so doing, we hoped to empower them further and allow them to influence the context of the research in this respect.

To this end, we hope our practical application and reflections on participatory research reported in the previous two chapters have contributed to the calls for a more systematic understanding of and reflection on how user participation is planned and managed: in particular, we hope we have expounded on our reasons (and benefits) for adopting a participatory research approach, illustrated how such participation can be planned and managed, elucidated on the challenges and methodological concessions necessary when engaging with older adults (with impairments), and fully articulated participants’ gains from taking part in participatory research projects. We hope that our observations are of value to others faced with the challenge of designing technology for special needs user groups via participatory design approaches.

Chapter 6. Developing the Diet Diary

6.1 Introduction

This chapter introduces the final interface design and functionality included within our prototype diet diary application. It also discusses and reflects on the process by which the application was implemented in Android in order to raise awareness of the contradictions that exist between UI design requirements as dictated by special needs users and technical mobile development platforms and norms catering to the masses. As discussed in Chapter 2, older adults' apparent lack of technological acceptance is often the result of the fact that current mobile devices are not designed with niche special needs users – such as individuals with AMD – in mind. We have (as reported in Chapters 3-5) used mixed method approaches to uncover the needs and preferences of our target users. This investigation has led to a clear prototype design for our proposed diet diary application together with a rich set of elicited user- and software-related requirements for our proof-of-concept diet diary application (see Chapters 3 and 4). It is argued that a balance between “*what is technologically feasible and what users value in a technology*” (Walton, 2003, p. 6) must be considered when designing and developing assistive technologies. The notion of users' ‘value’, however, should, by no means, include users' needs and preferences: to elaborate

on this matter further, this chapter provides a reflection on the technical challenges associated with attempting to build atypically-designed applications within the Android framework.

6.2 The Diet Diary Application Design

On the basis of the paper prototype designs generated as a result of our PD sessions (see Chapter 4), a proof-of-concept diet diary application was developed for the Android platform (see Appendix C for an overview of the application's structure). This section introduces the final application, illustrating its design and functionality via a walkthrough of the system.

Upon creating an account (see Figure 6.1 for the login screen: it is important to note that this screen was not designed during the PD activities as it was only later deemed important to create user accounts for identifying users and monitoring their activities) users are presented with the option of conducting a simple vision test using an Amsler Grid (a test used for

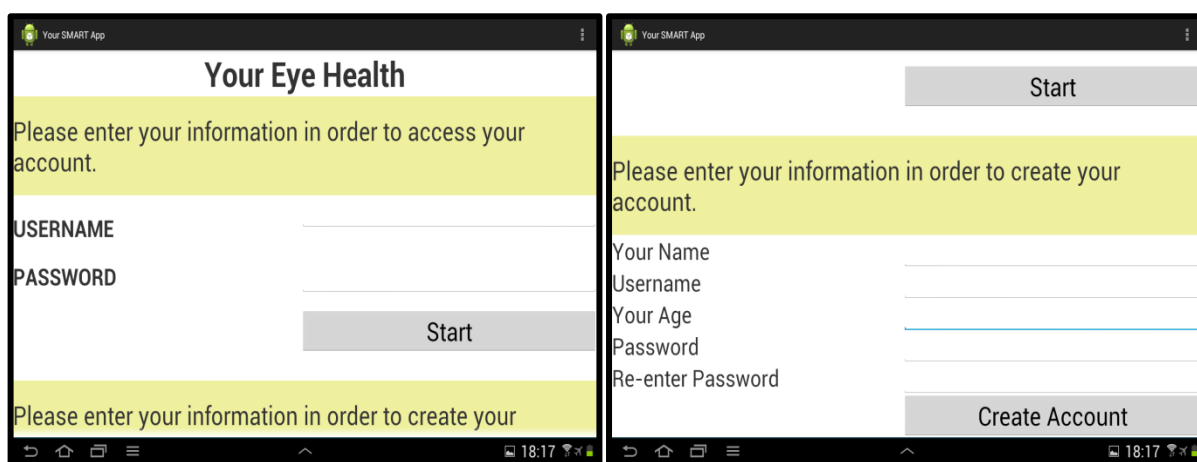


Figure 6-1: Login Page.

detecting and measuring extent of macular degeneration²) for the purpose of personalising the layout of the UI based on measured visual acuity.

The Amsler Grid looks like graph paper, with lines forming a square grid (see Figure 6.2). While staring at a dot in the centre of the grid, users are required to be aware of wavy lines

² <http://www.armd.org.uk/amsler.htm>

and missing areas of the grid within their vision and indicate (by touching those areas) the boundaries of their blind spot; assessing individuals' field of vision can prevent the placement of UI components where we know an individual user will not be able to see them easily – i.e., it supports bespoke customisation of the UI to the specific visual nuances of a given individual. Upon selecting the 'Continue To Your Account' option, users are presented with the 'Main Menu' screen.

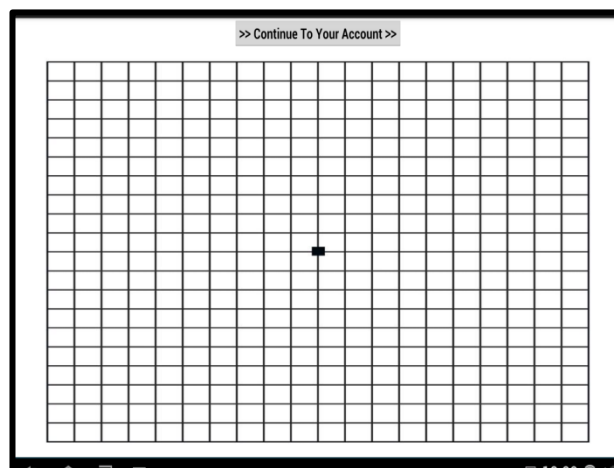


Figure 6-2: *Amsler Grid screen.*

Figure 6.3 shows the manifestation of our participant-designed 'Main Menu' screen once implemented in Android. The top panel of the screen is the action bar which preserves consistency across the application's different activities (i.e., screens), indicates the user's location within the app (by means of displaying the screen name), and makes essential actions/options accessible via all screens in a predictable way. The options (or action interactors) that have been placed on the action bar include today's date which provides access to view the calendar, an '*Alterations*' option for altering or making changes to the screen and personalising it (discussed further below), and a '*Logout*' option for exiting the application.

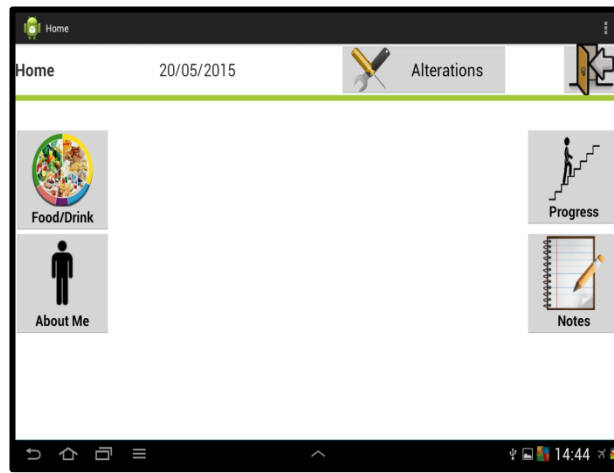


Figure 6-3: *Main Menu' screen within the prototype app*

As discussed in Section 4.5.2, in addition to the action bar the main screen also comprises a '*Food & Drink*' option for recording users' daily intake of food (see Figure 6.4). a '*Progress*' option for users to view their progress in terms of adherence to dietary recommendations and for accessing their recommendations (see Figure 6.5), an '*About Me*' option for users to record their personal data (see Figure 6.6), and a '*Notes*' option whereby users can 'store' their 'ideas' and thus support their memory (see Figure 6.7).

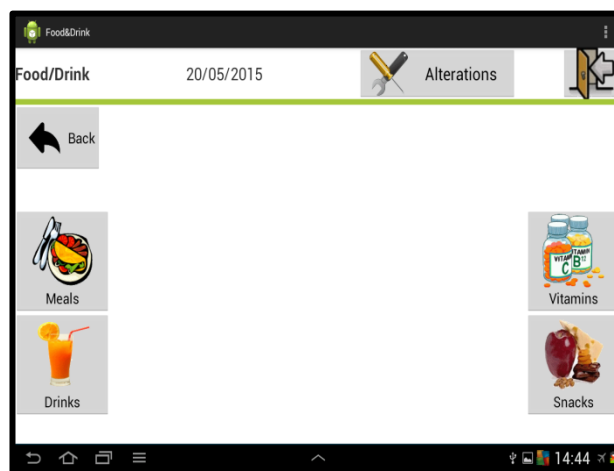


Figure 6-4: *Food & Drink' screen*

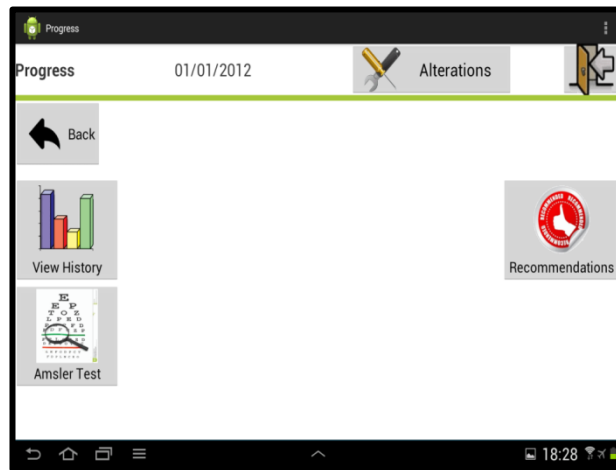


Figure 6-5:*Progress screen.*

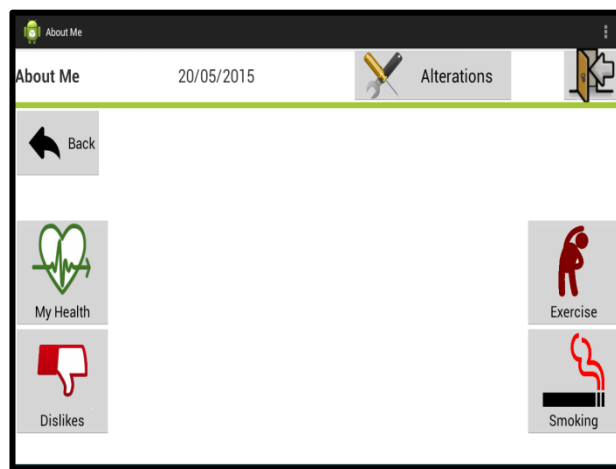


Figure 6-6:*About Me Screen.*

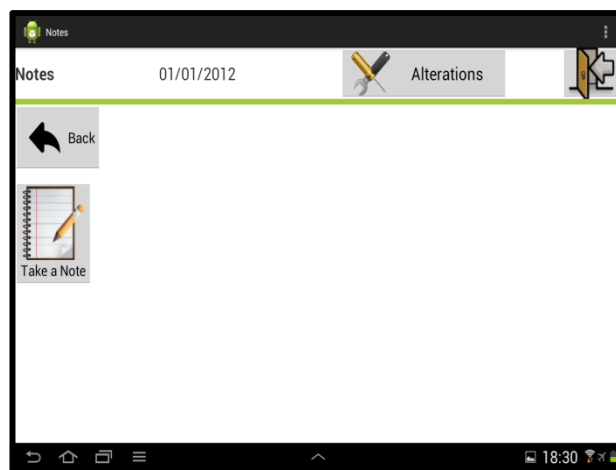


Figure 6-7:*Notes Screen.*

Via the 'Food&Drink' screen (Figure 6.4), users record their daily intake of food as meals, snacks and drinks, and also have an option to record intake of vitamin supplements (although not currently factored in recommendations, the intent is that information about vitamin supplements will be taken into account when providing customised recommendations in the future). Users select a food to enter by accessing the appropriate main food group and

then selecting the required, specific food from that group (see Section 4.5.2); the same concept also applies for entering drinks, snacks, and vitamin supplements (for examples, see Figures 6.8 and 6.9). It is important to note that, for the purpose of developing our simple prototype application, the type and number of food groups was set up to ensure the selection process remained very simple and to require users to focus on detail (as opposed to higher-level food group selection) only where necessary to support the AMD-related dietary recommendations sourced from the Macular Society (2014).



Figure 6-8: *Meals' screen to select appropriate food group*

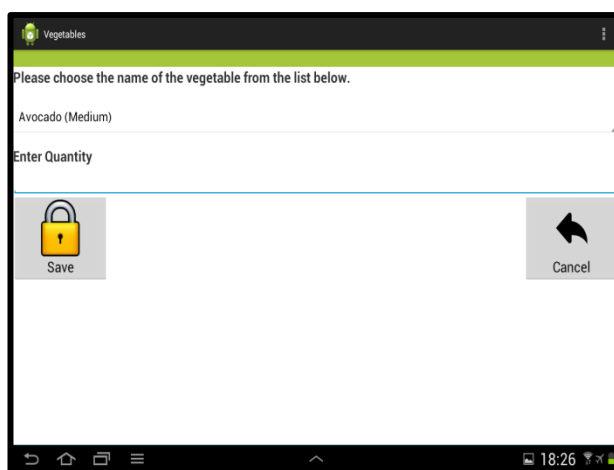


Figure 6-9: *Example of how a type of vegetable would be selected from the 'Vegetables' screen; the same process would be followed for other food/drink types.*

The 'Alterations' option/screen (see Figure 6.10), accessed via the action bar, facilitates personalisation of the app – that is, it enables users to individually tailor the application to better serve their needs and maximise application accessibility. From our fieldwork and design activities we learned that a black background was most beneficial to those users with the worst vision, whereas users with better eyesight preferred a white background. Thus the

option to change background was a core requirement (see Figure 6.11). Similarly, users have the option to change text size (see Figure 6.12).

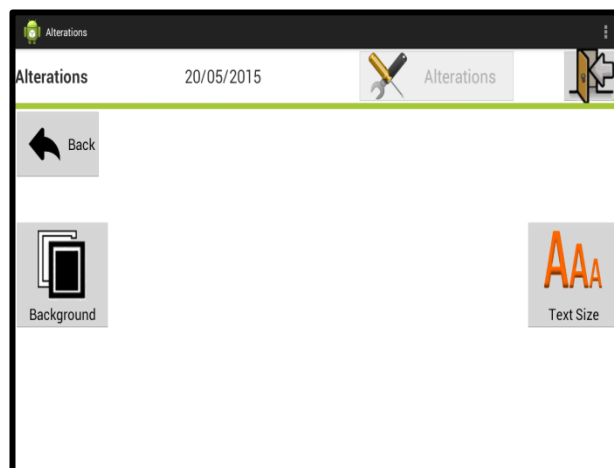


Figure 6-10:Alterations screen.

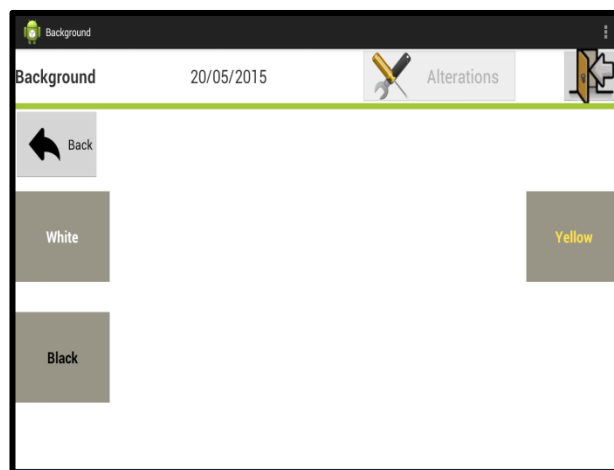


Figure 6-11: Screen to change the background colour.

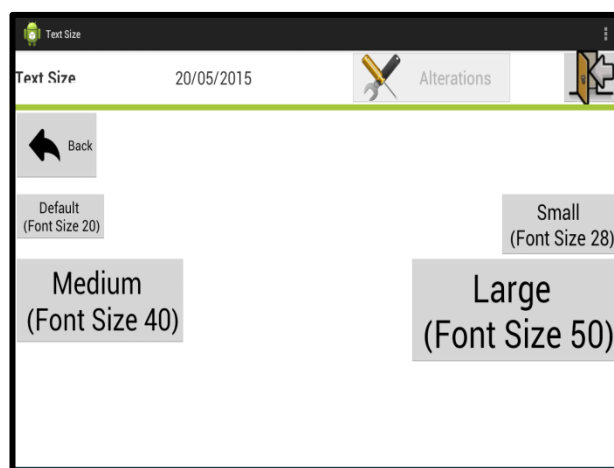


Figure 6-12: Screen to change the text size.

Another key aspect of personalisation is providing customised dietary advice and recommendations to empower people with AMD to make informed dietary choices. To

achieve this, on the 'About Me' screen (Figure 6.6) users record information about their medical condition ('My Health' option), disliked foods ('Dislikes' option) in order to avoid inappropriate or unwelcome recommendations and hence maximise compliance, level of exercise ('Exercise' option) and number of cigarettes smoked daily ('Smoking' option) – for the prototype, at this time only disliked foods are taken into account when providing customised recommendations (see Figures 6.13 - 6.15 for examples).

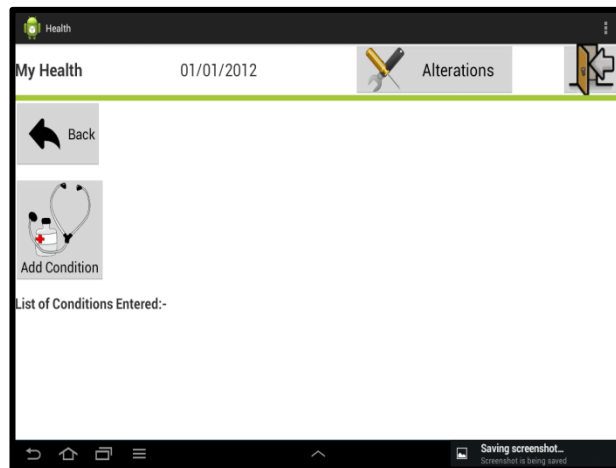


Figure 6-13: An example of how users would add health condition.

Figure 6-14: Pop-up window to record health condition.

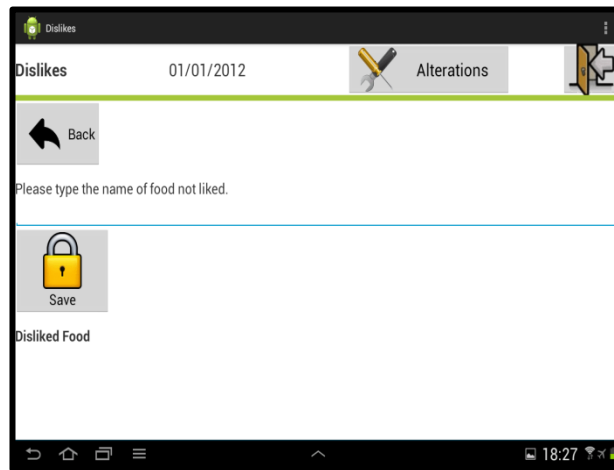


Figure 6-15: An example of how users would enter disliked food.

Additionally, users have a 'Progress' option (see Figure 6.5) for viewing their history in terms of adherence to dietary recommendations (see Figure 6.16), for accessing their recommendations (see Figure 6.17), and for taking an Amsler Test to monitor any changes in their vision (and encourage accurate UI recalibration where required).

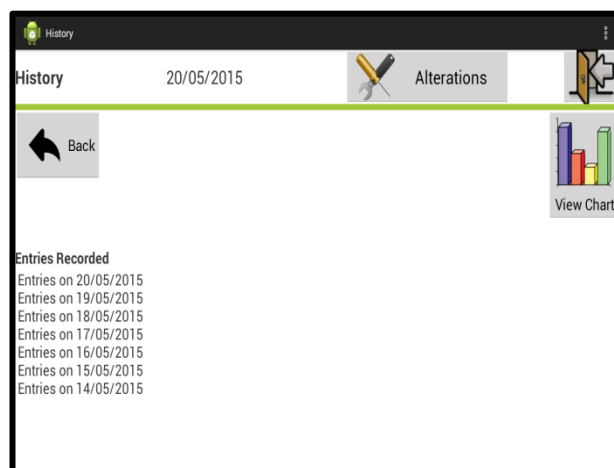


Figure 6-16: 'History' screen to view daily food recorded.

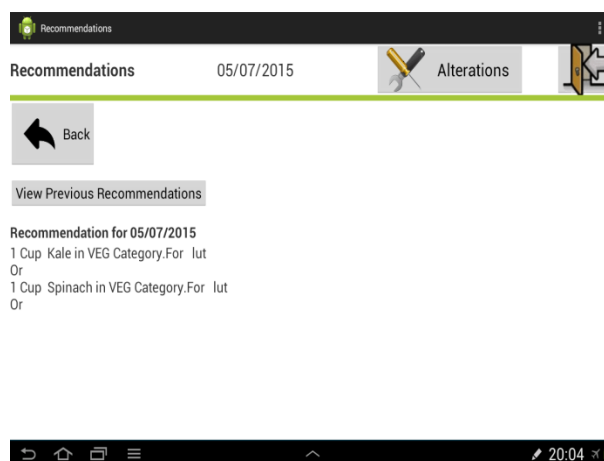


Figure 6-17: 'Recommendations' screen for accessing daily recommendation.

6.2.1 Design Modifications

In developing the proof-of-concept application, although we attempted to remain as true as possible to the design rendered by our participants during the PD sessions, some modifications (mainly due to Android's platform constraints and recommendations) between the paper and the Android app prototype designs were unavoidable. In an attempt to continue the participatory ethos of our research, where it was not physically possible to develop an element of the UI such that it was a true representation of the participants' designs, proposed alterations were discussed directly with the PD participants. Specifically, the researcher had two informal meetings (in their homes) with two of the participants (the other two participants could not be accessed due to ill health and holiday commitments). During these meetings, the need for alterations or extensions to their design was explained by the researcher and four main issues were then discussed (see below).

- The proposed login/sign-up screen was introduced to participants who agreed that, providing assistance was available during initial set-up, the design would be manageable.
- The date placed on the action bar would display the current date as opposed to facilitating date selection (to adopt a simple application structure and minimise development time).
- The pop-up option was introduced for recording health conditions (and taking notes). As with the login screen, the UI design of this screen was not discussed/rendered during the PD activities. For taking notes, it was initially agreed to allow users to take a picture for storing notes, but upon reflection, participants raised concerns about having to "*leave*" the application to view the images, and agreed to try-out "*typing*" the notes option. As for health condition, it was merely a placeholder that participants considered to be necessary for when the application is commercialised (see Chapter 9): implementation of this would require a close collaboration with health professionals to understand how this type of information should be recorded (i.e., to what extent are patients aware of their health conditions?), and how this should be incorporated within the recommendations algorithm to ensure that food

recommendations reflect and incorporate participants' other health-related dietary requirements.

- To keep the proof-of-concept application simple (and due to time constraints) the voice recognition and touch gesture (to zoom and move elements on the screen) options suggested on the 'Alterations' screen were not implemented. Instead, the 'Alterations' screen (with options for changing background screen and text size) was made prominent and easily accessible on all screens via the action bar (as per the Android Design Guidelines discussed in Section 6.4) (see Figure 6.3 for an example).

6.3 Implementation: The Android Application Framework

The application was developed for the Android platform in part because of its flexibility across a range of devices and manufacturers, supporting greater ultimate choice in device size and price, etc. Android is an open mobile operating system (OS) freely available to all developers. The Android OS architecture consists of the following building blocks required for building an Android application: (1) Application layer where all Android applications (including our diet diary application) are installed; (2) The Application Framework which provides higher-level services to applications (e.g., content sharing between applications, use of GPS); (3) Libraries, which manage different types of data (for example, our diet diary application makes use of the available SQLite database for storing data); (4) Android Runtime, which enables developers to write Android applications using the Java programming language; and the (5) Linux Kernel, which provides basic system functionality (e.g., memory management) and acts as an abstraction layer between the hardware and other software layers.

The Eclipse Integrated Development Environment (IDE) was used to develop the diet diary proof-of-concept application. Implementation comprised the development of the aforementioned UI (based on the designs generated from our PD sessions) as well as the development of a computational engine (back-end) that included the creation of a simple

food and associated nutritional ontology together with the daily nutritional recommended intake based on nutritional information sourced from the Macular Society (2014), and the development of a rule engine that combines information from the ontology with data from user profiles (currently restricted to food preferences, but future plans would be to integrate medical condition and age information as well) and captured dietary data (i.e., daily food entries) to generate individualised recommendations. Extensible Markup Language (XML) files used to render the interface of the application: UI layouts are declared in XML (this also includes the screen elements (i.e., buttons, icons, text fields) and their properties (e.g., size, position, colour)). This type of declaration (as opposed to creating layouts programmatically) isolates the presentation of the application from the code that controls its behaviour (for an example of the XML layout declaration for the action bar, see Figure 6.18). The back-end of the application is constructed in Java and a DBAdapter class creates an SQLite database for storing and handling data.

```
<TableLayout
    android:id="@+id/TL1"
    android:layout_width="fill_parent"
    android:layout_height="wrap_content"
    android:layout_gravity="center"
    android:stretchColumns="*" >
<TableRow android:background="#FFFFFF" >

<TextView
    android:id="@+id/home"
    android:layout_width="wrap_content"
    android:layout_height="wrap_content"
    android:layout_weight="1.0"
    android:text="Home"
    android:textSize="24sp"
    android:textStyle="bold" />

<TextView
    android:id="@+id/date"
    android:layout_width="wrap_content"
    android:layout_height="wrap_content"
    android:layout_weight="1.0"
    android:text="Date"
    android:textSize="24sp" />

<Button
    android:id="@+id/button2"
    style="?android:attr/buttonStyleSmall"
    android:layout_width="130dp"
    android:layout_height="90dp"

    android:drawableLeft="@drawable/action_alterations"
    android:onClick="Setting"
    android:text="@string/btnAlterations"
    android:textSize="24sp" />

<Button
```



```

android:id="@+id/helpbtn"
style="?android:attr/buttonStyleSmall"
android:layout_width="20dp"
android:layout_height="match_parent"
android:layout_gravity="right"
android:drawableRight="@drawable/log1"
android:onClick="Logout" />

```

Figure 6-18: Example of the XML layout declaration of the action bar.

The DBAdapter class was used to create the following tables within the database for storing relevant information:

- **food_master:** stores food name, type, portion (usually the amount consumable within a single portion/meal) and nutritional value;
- **food:** stores daily intake of food per user;
- **login (users):** stores username, encrypted password, all profile information (e.g., name and age); and
- **health, dislikes, smoking, notes:** stores fields associated with each data type, along with the user ID of the corresponding user.

The core functionality of the application is implemented via custom Java files (stored in the source folder of the application). A `dispatchTouchEvent(MotionEvent ev)` method provides functionality for capturing and monitoring user interaction (this can then support UI adaptation) on all java files. A `MotionEvent` class is responsible for detecting movement (i.e., gesture/touch) events, which are described in terms of a set of axes values. When the user touches the screen, the system delivers a touch event to the appropriate `View` with a set of axes values that include the X and Y coordinates of the touch position; the position of the touch is queried via `getX(int)` and `getY(int)` methods (see Figure 6.19). This data can then be compared with the UI components' X and Y coordinates to facilitate UI adaptation based on detected changes.

```

[...]  

int counter=0;  

@Override  

public boolean dispatchTouchEvent(MotionEvent ev) {  

    if(counter%2==0){  

        float x = ev.getX();  

        float y= ev.getY();  

        DBAdapter_smoking dba = new DBAdapter_smoking( this);  

        dba.open();  

        long dislikeid= dba.insertrow(id," Pointers at ( " + x + " , " + y + " )" );  

    }  

}

```

```

        dba.close();
        Log.d("", "Pointers at ( " + x + " , " + y + " )" );
    }
    counter++;
    return super.dispatchTouchEvent(ev);
}
[...]
```

Figure 6-19: Example `dispatchTouchEvent(MotionEvent ev)` method for detecting touch point coordinates

To generate personalised recommendations for each type of key nutrient (i.e., Omega-3, Zinc, B vitamins, vitamins A, C and E, Lutein), the `foodmorethantoday` method combines ontology information with data from user profiles (such as disliked foods) and captured dietary data (i.e., daily food entries), and compares this to the recommended daily intake of nutrition (as sourced from the Macular Society³ and Nutrition For Healthy Eyes⁴ online resources (see Figure 6.20 for an example)).

```

public void foodmorethantoday(String date)
[...]
```

```

    if((Float.parseFloat(cd.getString(4))>req_vitc)&&(req_vitc>0)){
        flag =0;
        for(int i=0; i<20;i++){

            if((cd.getString(2)).equals(dislike[i])){

                Log.d("", "flag "+ flag);

                flag=1;

                break; }}
[...]
```

Figure 6-20: Sample code comparing recommended nutritional intake for vitamin C.

In the event that a user's captured intake of a given nutrition is less than the recommended daily intake of that nutrition, the `gettodayfood` method generates personalised recommendations for the user to encourage increased consumption of the nutrient in question (see Figure 6.21).

```

public void gettodayfood(String foodtype){
[...]
```

```

    DBAdapter_food dba = new DBAdapter_food( this);
    dba.open();
    Cursor cd = dba.getfilterrecordProgress(id, foodtype);
    if(cd.moveToFirst()){
        do{
            [...]
            today_vitc=today_vitc+ Float.parseFloat(cd.getString(6));
[...]
```

³ <http://www.macularsociety.org/nutrition/Nutrients>

⁴ http://www.allaboutvision.com/nutrition/nutrition_summary.htm

```
count ++;  
}  
while (cd.moveToNext());  
}  
dba.close();  
[...]
```

Figure 6-21: Example code generating recommendations for vitamin C.

6.4 Limitations and Challenges

Since platform design and development norms did not necessarily lend themselves to honouring the atypical design requirements of our app, we had to devise programming workarounds to implement a design concept that typically ‘broke’ established design norms and Android design recommendations. One of the main difficulties associated with the use of Android for developing this prototype was that the researcher could not take full advantage of the comprehensive guides and support resources available for Android developers online⁵. This, in turn, introduced delays to the implementation phase of the project, as the researcher had to acquire the programming skills necessary for achieving an aesthetically ‘unusual’ application design.

For example, whilst the Android action bar supports consistent navigation, and has the capacity to reduce clutter by providing an action overflow for rarely-used actions, we had to ‘bend’ Android’s rules for this action bar to achieve the atypical design required for our app: Android design guidelines strongly recommend placing only icons on the action bar whereas we needed, based on our participants’ preferences and requirements, to include both iconic and textual representations of functionality. Furthermore, to achieve our participant-derived design, we had to ignore Android’s recommended use of non-obvious interface elements, nested menus, reliance on long touches and hardware menu buttons when converting our paper prototype into a proof-of-concept application.

Other issues associated with instantiating the design in Android included the restricted placement of pop-up menus given that they are anchored to the base class of Layouts in

⁵ <http://developer.android.com/support.html>

Android: we could not find a workaround for this to allow flexibility in displaying the pop-up menus.

A further issue is associated with the software fragmentation of the Android OS: since its first release in 2007, 12 different Android OS versions have been developed. This presents challenges for developers, as supporting earlier versions of the Android OS would make the application compatible with a larger number of devices but would restrict it from taking advantage of new features and functionalities available on later versions. For the purpose of developing our proof-of-concept diet diary application, we decided to develop for one of the earlier versions of the OS due to its applicability across a range of devices and manufacturers given that older adults are less likely to have the latest, state-of-the-art Android devices.

The above issues led us to reflect on the extent to which the final stage of development is 'strangled' by technology norms such that control placed in the hands of the users during design ebbs away when faced with the practicality of delivering a working system. Nothing that we were trying to achieve was theoretically difficult, yet the framework imposed by Android made achieving an atypical, well-informed yet aesthetically 'unusual' design somewhat of a struggle.

In terms of the prototype itself, one of the main limitations includes the simplicity of the food ontology created. It only holds a limited number of food ingredients and products as opposed to a more comprehensive, accurate and complete ontology (or food database) which also holds nutritional data for meals and recipes and permits the user to record food products and meals not included in the database. A dietary supplement assessment module is included so nutrient intake from both food and supplemental sources may be captured and quantified.

A further limitation is the rule engine which combines information from the food ontology and only restricted data (i.e., recorded daily intake of food and disliked food ingredients) from a

user's profile to generate individualised recommendations. Whilst what we have developed serves the purpose of supporting evaluation of the principle of the application recommendations, for a more robust recommender algorithm, additional factors should also be taken into consideration when generating personalised recommendations. These include, but are not limited to the following:

- nutritional needs of individual users based on their medical condition(s) (e.g., blood pressure, cholesterol levels);
- any supplements, vitamins or medications taken by the user;
- information about user's lifestyle (e.g., smoking habits, activity level); and
- accurate nutritional information of meals (and other food consumed) not included in the database but added by the user.

Overall, while the rendered UI design closely mirrors our co-designer participants' designs, the back-end of the application could benefit from future expansions and enhancements (see Chapter 7 for our participants' suggestions for future enhancements to the application) to ensure legitimacy and comprehensiveness of the provided recommendations.

6.5 Android Design Guidelines

Having reflected on our challenges encountered when developing an atypical application for Android's platform, this section reviews Google's Android Developer Guidelines (Android, 2014) in an attempt to reflect on the extent to which these guidelines intrinsically support design for older adults in general. Table 6.1 summaries Android's main design principles.

Table 6-1: *Android Design Principles.*

Principle #1: Enchant Me

| | |
|-----------------------------------------------------------|-----------------------------------------------------------------------------------------|
| <i>"Delight me in surprising way"</i> | Suggests subtle effects such as animations and sound effects. |
| <i>"Real objects are more fun than buttons and menus"</i> | Suggests direct manipulation of objects. |
| <i>"Let me make it mine"</i> | Advises designers to allow customisations that don't hinder primary tasks. |
| <i>"Get to know me"</i> | Encourages learning users' preferences over time to avoid asking them for same choices. |

| | |
|-------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------|
| Principle #2: Simplify my life | |
| <i>"Keep it brief"</i> | Encourages the use of short phrases with simple words. |
| <i>"Pictures are faster than words"</i> | Suggests the use of pictures to explain the words. |
| <i>"Decide for me but let me have the final say"</i> | Suggests allowing for 'undo' avoiding too many choices and decisions. |
| <i>"Only show what I need when I need it"</i> | Suggests breaking tasks and information into small, digestible chunks, hiding options that aren't essential for the task at hand. |
| <i>"I should always know where I am"</i> | Encourages making places in the app look distinct and providing feedback on tasks in progress. |
| <i>"Never lose my stuff"</i> | Advises remembering of settings, personal touches, and creations across multiple devices. |
| <i>"If it looks the same, it should act the same"</i> | Encourages making functional differences visually distinct rather than subtle. |
| <i>"Only interrupt me if it's important"</i> | Suggests avoiding unnecessary interruptions unless critical and time-sensitive. |

| | |
|----------------------------------------------|-----------------------------------------------------------------------------------------------------------------|
| Principle #3: Make me amazing | |
| <i>"Give me tricks that work everywhere"</i> | Encourages making apps easier to learn by leveraging visual patterns and muscle memory from other Android apps. |
| <i>"It's not my fault"</i> | Encourages the use of clear recovery instructions without any technical details. |
| <i>"Sprinkle encouragement"</i> | Encourages the use of feedback. |
| <i>"Do the heavy lifting for me"</i> | Advises making novice users feel like experts by enabling them to do things they never thought they could. |
| <i>"Make important things fast"</i> | Suggests making important actions easy to find and fast to use. |

In addition to the aforementioned general design principles, designers/developers are also strongly encouraged to consider the guidelines outlined in Table 6.2 to ensure that their app is conforming to the standard Android visual design and interaction patterns for a more consistent user experience across apps.

Table 6-2: *Android visual design and interaction patterns.*

| | |
|----------------------------------------------------------------------------------------------------------------------------------------------|--|
| "Don't mimic UI elements from other platforms" | |
| Designers are encouraged to follow Android OS's style and design patterns to learn about its different themes and corresponding UI elements. | |
| "Don't carry over platform-specific icons" | |
| Designers are encouraged to use Android's platform-specific set of icons for common functionality. | |
| "Don't use bottom tab bars" | |
| Instead of using a bottom tab bar to switch between the app's views, Android uses a persistent action | |

bar at the top of each screen throughout the app. Recommendations for implementing action bars include the use of standard, unlabelled icons and splitting the action bar into four different functional areas: app icon (to establish the app's identity), view control (to switch views), action buttons (to show most important actions of the app), and action overflow (to include less used actions).

“Don't hardcode links to other apps”

Explicit links to particular apps are not optional.

“Don't use labelled back buttons on action bars”

In place of using an explicit back button with label to allow the user to navigate up the application's hierarchy, Android uses the main action bar's app icon for hierarchical navigation and the navigation bar's back button for temporal navigation.

“Don't use right-pointing carets on line items”

The display of right-pointing carets on line items for allowing the user to drill deeper into additional content is not recommended.

The aforementioned guidelines and recommendations undoubtedly serve as a useful baseline in terms of how Android applications should look and feel to achieve consistency across the platform; they do not encourage major deviations in user interface designs. This, in turn, raises questions about the applicability and adaptability of these guidelines when designing applications for older adults (with impairments) for whom standard design norms are not necessarily meaningful or appropriate. To render Android apps accessible to users with a wide range of abilities, designers are recommended to adhere to universal design principles (see Section 2.5.1), utilise Android's accessibility tools such as ‘TalkBack’⁶ and ‘Explore by Touch’⁷ (both pre-installed screen reader services), and manage accessibility settings (e.g., increase font size, colour adjustment, text-to-speech options, etc.) available on Android devices. While accessibility features such as ‘TalkBack’ and the ‘Explore by Touch’ might be beneficial to older adults with visual impairments, the universal design principles may not all apply when designing (assistive) technologies for older adults with a variety of (dis)abilities and experiences, due to the underlying concept that the design of technology should be accommodating to people with a range of (dis)abilities and, thus, no user should be excluded from the use of technology (as discussed in Section 2.5.1). One of the realisations, however, emerging from the discussion reported in Chapter 2 was the

⁶ <http://www.androidcentral.com/what-google-talk-back>

⁷ <https://support.google.com/accessibility/android/answer/6006598?hl=en-GB>

heterogeneity of older adults' capabilities, both across and within a given impairment and the need to target designs specifically to cater to these capabilities (as opposed to the capabilities of the general population). This leads to the formation of a niche market that requires personalised, specific technology to meet individual needs and capabilities of specific users; thus the aforementioned recommendations are not sufficient to support developers/designers concerned with designing applications for specific user groups, such as older adults (with impairments).

Not all of the aforementioned principles can be effectively adopted and applied when designing for older adults. For instance, the guidelines encourage the use of standard, unlabelled icons in the action bar and, generally, the use of pictures instead of words: we found, from our knowledge elicitation (see Chapter 3) and design (see Chapter 4) activities, that icon designs and naming conventions used within current applications are not consistent with older adults' mental models based on their life experiences, familiar environments and use of everyday objects and as such served no useful purpose for them. Using unlabelled controls within an application could potentially confuse users, especially older adults who might not be familiar with the controls conventionally used across Android applications. Similarly, the use of pictures (albeit intuitive and self-explanatory) without associated labels could raise questions and confusion about the intended purpose of their use within the specific context of the application.

Similarly, recommendations to hide options that aren't essential, and only displaying what is necessary for the task at hand, should also be observed with caution when designing for older adult users. This suggests reliance on nested menus (including the navigation drawer pattern, which slides in from the left of the screen and might change depending on the state of the application), multi-pane layouts (which are more applicable to larger devices such as tablets) and hardware menu buttons, all of which might not be intuitive to older adults. Reliance on hardware menu buttons (essentially the three permanent controls available at the bottom of the screen on Android devices – i.e., back, menu, and home), in particular,

could raise further questions about the visibility, accessibility and consistency of an application's functionality for older adults. While these controls are always visible, they are not always all active nor do they always result in the same effect when triggered (Norman and Nielsen, 2010). For instance, the menu control may not always display the same menu for all screens across the application, or may not result in the display of a menu on particular screens depending on a given application's structure. Furthermore, hardware menu options on current Android devices (including tablet devices) are relatively small in size making it hard for older adults to detect and interact with these (further discussed in Chapter 7), particularly for older adults with visual impairments (e.g., Guerreiro, 2010) and motor impairments who may have lower precision (e.g., Guerreiro *et al.*, 2010) and, thus, find the interaction somewhat troublesome.

Finally, Android's recommendation to use the app icon and navigation bar's back button for hierarchical and temporal navigation as an alternative to explicitly labelled back buttons can also be very burdensome for older adults. While our participants' design (and the subsequent Android application) did include an explicitly labelled back button on every screen to use for navigation, one of the most common and bothersome hardware-related concerns raised by our participants during the evaluation studies (reported in Chapter 7) was the accidental instigation of the return button on their devices. This is primarily because: (a) when pushing the on-screen back button, users (particularly older adults who are not familiar with Android OS) expect to be taken back only one screen, whereas the app icon takes the user all the way back to the main menu (i.e., "home" screen); (b) accidentally pushing the navigation bar's back button two to three times can also take the user out of the application as opposed to navigating the user through the history of screens visited; and (c) due to the small size and typically fixed nature of the hardware or navigation bar's back button older adults may find it challenging to identify, locate and activate it (particularly when age-related impairments result in declined sensation of touch (Wickremaratchi and Llewelyn, 2006)).

Some of the Android principles more pertinent to the needs of older adults include the possibility for customisation and learning users' preferences over time. Personalisation can empower older adults to better adapt technology to their needs and capabilities; this can, in turn, make technology more aesthetically pleasing to them. Similarly, adaptable design (in terms of learning users' preferences) of technology can potentially withstand continual capacity/capability changes older adults may experience over time due to ageing. Due to older adults' reduced rate of learning (Renaud and van Biljon, 2010), Android's recommendations for simplified designs with reduced functionality (with the possibility of additional functionality when required), accessibility of important actions, making places in the app look distinct, and providing feedback on tasks in progress could all make the resulting technology more accessible for and acceptable to older adults.

Based on the above discussion it is evident that, due to the lack of availability of comprehensive guidelines that are sympathetic to older adults' (with impairments) needs and capabilities, special considerations need to be taken into account when designing UIs for this user group such that the limitations imposed by the design platform (i.e., the Android OS) and the hardware itself can be overcome. Researchers have recommended taking into account the following key issues when designing for older adults (Fisk *et al.*, 2009):

- consider older adults' range of abilities and experiences;
- ensure user goals and expectations match system functionality;
- consider how best to organise and present information and compatibility issues;
- provide tools to minimise potential navigation issues; and
- provide informative documentation for the system including error messages, user manuals and help systems.

Although these are more general guidelines and do not provide concrete examples of how technology for older adults must be successfully designed (i.e., in terms of styles, navigation, layout patterns, UI components), when combined with some of Android's more pertinent design guidelines (as discussed above), it could potentially provide a basic starting point for

designers and app developers. That said, more research is required to generate a comprehensive set of guidelines for the design and development of mobile applications for older adults grounded on empirical, as well as theoretical, evidence.

6.6 Summary

The prototype diet diary application has been developed in an attempt to promote independent living and enhanced wellbeing for older adults with AMD. A novel UI (based on our participants' paper prototypes) for the application has been developed in an attempt to maximise the accessibility of the application for this user group. Finally, a facility within the application has also been developed for conveniently recording dietary information and automatically providing customised dietary advice drawing on evidence-based recommendations and captured data to empower ageing persons with AMD to make informed dietary choices. Reviewing Android's standard conventions or guidelines for developing applications for this platform led us to question the derivation of the Android guidelines/norms, and their applicability beyond a 'normalised' user group. Android made achieving an atypical, well-informed yet aesthetically 'unusual' design a struggle – resulting in some compromises and leading us to question the extent to which special needs users' control (as part of a research project such as ours) extends to the delivery of a system, and highlighting the need for more comprehensive guidelines and recommendations tailored to the needs of niche user groups such as the older adults (with impairments).

Chapter 7. Evaluating the Diet Diary

7.1 Introduction

Our diet diary application is essentially a high-fidelity interactive prototype of a mobile assistive technology concept, the goal of which is to provide customised advice and recommendations to people with AMD to help them make informed dietary choices in an attempt to mitigate their ongoing risk and retard the progression of their disease. From a research perspective, the process of creating the prototype application was an instrument for studying aspects of technology design, development, and adaptation for older adults with special needs. Chapter 5 has already evaluated and reflected on the design process components of the overall process. In this chapter, our evaluation focuses on the usability of the resulting design; the following chapter evaluates and reflects on the procedural efficacy in terms of running such evaluations with our target user group.

This chapter details the research design and methods used as part of a usability evaluation study that was conducted in two separate phases between August and December 2014 to collect empirical data to support investigation of the usability, acceptability and initial impact indicators of the prototype application; analysis of the data is also documented in this

chapter. As with all previous studies reported in this thesis, ethical approval for this phase of the overall research agenda was obtained from the Aston University REC (see Appendix D.1).

Phase 5 of the overall research agenda (the initial phase of our usability study reported here) comprised a preliminary week-long study during which the diet diary application was introduced to representative target users (i.e., older adults with AMD) in order to elicit their initial reactions to it, and to invite potential participants to participate in the longitudinal phase of the evaluation study (Phase 6).

Phase 6 was a 6 week long longitudinal field study which aimed to assess the acceptability of the proposed application, to identify factors *predicting* adherence to dietary recommendations, and to identify early indicators of the impact of use of the diet diary.

We concluded our evaluation activities with a focus group-based study, the aim of which was to address a methodological knowledge gap in the field of HCI concerning how best to ‘end’ participatory research. Cognisant of the potential negative effect that withdrawal of the participatory process may have on individuals who have been heavily engaged in such research and benefited from such engagement (such as our older adults with AMD), we consulted our participants regarding their perspectives on how to bring closure to the process in as positive a way as possible. This phase (Phase 7) is discussed in Chapter 8.

7.2 Phase 5: Preliminary Evaluation Study

The main purpose of our preliminary evaluation study activity was to introduce our diet diary application to representative target end users (i.e., older adults with AMD) in order to elicit their initial reactions to it and to invite potential participants to participate in the longitudinal evaluation study that was to follow.

We invited three of our existing PD participants who had a strong working relationship with the researcher and were keen to “*test their designs*” to participate in this phase of our research. Via word of mouth, two other participants with AMD approached us to participate, and were included in the study. Finally, we approached the Aston Research Centre for Healthy Ageing (ARCHA) to recruit participants on our behalf from their panel of older adult volunteers. A coordinator for the centre circulated study information (see Appendix D.2) to panel members and interested participants were asked to contact the researcher to discuss taking part in the study. While the response from potential participants through this channel was promising, only 6 prospective participants were initially identified as suitable candidates for the study; of these, two were discounted during one-to-one discussion (outlined in the following subsection) when it was discovered that they suffered from other types of visual impairment (not AMD) and as such did not meet our inclusion criteria. Hence, in total, 9 participants (see Table 7.1 for participants’ characteristics) were enrolled in the study with a gender split of 6 women and 3 men; participants’ ages ranged from 65-89 (mean age 77).

Table 7-1: Overview of study participants’ characteristics (participants from previous design phases are highlighted in blue).

| ID | Age | Gender | Experience with Computers | AMD Severity | Number of Years Since Diagnosed |
|----|-----|--------|---------------------------|----------------------------|---------------------------------|
| P1 | 74 | Female | Some | Unknown | 3 |
| P2 | 87 | Female | None | Wet one eye, dry other eye | 10 |
| P3 | 89 | Female | Some | Dry one eye | 8 |
| P4 | 72 | Male | Moderate | Wet both eyes | 4 |
| P5 | 65 | Female | Moderate | Dry one eye | 2 |
| P6 | 73 | Male | Some | Wet one eye | 4 |
| P7 | 78 | Male | None | Wet one eye, dry other eye | 12 |
| P8 | 72 | Female | None | Dry both eyes | 14 |
| P9 | 81 | Female | Some | Dry one eye | 3 |

7.2.1 Study Protocol

As with all phases of this research project, care was taken to ensure the comfort of participants at all times. All prospective participants were initially contacted by phone by the researcher, at which point initial introductions were made to both the researcher and research. After this initial level discussion, those who expressed an explicit interest in participating were then invited to an informal, one-to-one information session (typically lasting 1-2 hours) which provided prospective participants with an opportunity to meet the researcher (particularly important for the new participants as opposed to the continuing participatory group members), to be introduced to the diet diary application, to receive an overview of the study in general and what would be expected of them should they decide to participate, and to ask any questions they had. As already noted, for most of the participants the researcher visited them at their homes to run the sessions; only 3 participants, at their own request, arranged to visit the researcher at the University instead.

Those who then agreed to take part in our Phase 5 study were provided with consent forms and an information sheet (see, Appendix D.3) which clearly outlined in writing that which had been discussed verbally, namely the aims of the study, the expectations of their participation, and ethical considerations, such as how confidentiality and anonymity would be affirmed. The participants were then given as long as they needed (no less than 3 days) to review these details (with family members where applicable) and contemplate their participation in order to arrive at an informed, voluntary decision as to whether or not to participate. Once they had had time to reflect on their participation, the researcher contacted them (via phone call) to learn of their decision; for those who wished to proceed, the researcher arranged to visit them at a time and location appropriate to each individual (only one participant chose to meet the researcher at the University, all others opted for home visits).

During these visits (typically lasting 1-2 hours), each participant was provided with a mobile device running our diet diary application, and was instructed on the use of both the device and application. The researcher set up the device (participants had an opportunity to select

from three different device sizes – 5”, 7” and 10”) and the application for each participant; this included creating a user account and setting up the customisation to ensure the application was optimised to its ‘user’. Each participant was then given time to ‘play’ with the app and ask questions to ensure they were comfortable with it. Participants were then informally interviewed to establish their starting-point subjective opinion of the app in particular, and technology in general, in terms of usability and acceptability, their perception of their own state of vision and health, and their nutritional habits and beliefs. They were asked to use the application as part of their daily routine for the subsequent 7 days to both provide initial feedback to the researcher and to help them decide if they would like to continue into the longitudinal study. It is important to note that participants were not requested to use any particular feature(s) of the application for any specific period of time; they were merely asked to use the application as it suited them in order to see how well it fit within their daily routine and to determine what features they gravitated naturally towards using; participants were given the researcher’s contact details should they encounter any difficulties, have questions, or want to withdraw from the study and advised that they could contact her at any time, regardless of the issue.

At the end of the week, each participant was interviewed again (time and location at the discretion/preference of the individual) to identify shortcomings and areas for refinement in the application itself, and to invite the participant to continue into the longitudinal study if they so wished. In both start- and end-point interviews, participants were encouraged to have a family member/friend present if they wished: only one participant invited her daughter to be present for the end-point meeting. Interviews were all informal to ensure participants felt at ease: handwritten notes were taken.

The qualitative data from all three summative evaluation phases (Phases 5-7) of data collection was handled in the same way. The start- and end-point interviews were audio recorded and later transcribed. During intermediate meetings (e.g., weekly meetings as described in Section 7.3) with participants, handwritten notes were taken, and later added

into the transcription record. The qualitative data was anonymised via the use of codes. To ensure that participants are not identifiable in discussion of the findings, ‘participant’ or their respective codes (e.g., P1) have been used for reporting purposes. It should be noted that none of the quotations transcribed contained specific references to people, places, or similar that could result in the participants being identifiable.

The AV recordings of the study sessions were also transcribed and the transcripts were validated by a third party to confirm accuracy and completeness. All qualitative data collected was subjected to thematic analysis (Braun and Clarke, 2006) to enable us to identify patterns across the dataset and afford a representation of participants’ experiences of using the diet diary application (see Chapter 5 for explanation of the process used). Table 7.2 provides an example of how codes were applied to data extracts as part of this process (see Appendix D.4 for full data analysis for Phase 6 of the study).

Table 7-2: Examples of data extracts with codes applied.

| Data Extracts | Coded As |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>“It’s up to you, it’s up to you, the choice is yours. You can go out or stay at home and keep twiddling my thumbs. I was busy like you when I was 30 and it does get better. You need something to register, to keep your brain cells busy”.</i> | <ol style="list-style-type: none"> 1. Stimulates learning 2. Keeps brain active 3. Acceptance of the condition 4. Affirmative and hopeful attitude 5. Shows strength of character |
| <i>“If you don’t do it for you, do it for the community!”</i> | <ol style="list-style-type: none"> 1. Keen to help others 2. Considering others’ needs |
| <i>“I think you have to have a routine with it, especially if you make your mind up teatime”.</i> | <ol style="list-style-type: none"> 1. Importance of routine 2. Usage style |
| <i>“I prefer to do it this way [writing on the paper first], otherwise you can’t remember what’s in your brain. If you try to remember what you had ... ok you could do it after every time you eat, but I prefer this way.”</i> | <ol style="list-style-type: none"> 1. Usage style 2. Importance of routine 3. Health concern - memory |
| <i>“I’m getting on alright but not good enough for me [talking about the tablet use]. I have high expectations of myself [laughs] and I think you have as well high expectations.”</i> | <ol style="list-style-type: none"> 1. Determined to succeed 2. Evidence of self-efficacy 3. High expectations 4. Considering researcher’s expectations |

7.2.2 Findings and Discussion

7.2.2.1 Profile of Participants

In terms of living arrangements, all our participants lived on their own and were responsible for doing their own shopping and food preparation. When asked about their subjective opinions on their own general health, only 3 participants described it as “good”; others were less optimistic and noted that, while they were coping with it, it could have been better (but did not elaborate on any issues). In terms of their diet, the most important factors that dictated their intake of food included “*preference*” (56%), “*cost*” (33%) and “*ability to prepare it*” (11%). Less than half of the participants (44%) (of which three were our PD participants) expressed interest in changing their diet, identifying “*physical impairment*”, “*habit*” and “*willpower*” as the main barriers to diet change. Interestingly, the newly-recruited participants also expressed hope that the diet diary application could encourage such change; this suggests that the goal of the app has some resonance with its intended user group.

When asked if they felt that people with AMD are currently given sufficient information on how nutrition can affect their eye health, 5 out of the 9 participants disagreed, 2 believed it was “*getting better*”, and only 2 agreed that sufficient information was available. This seems to echo findings from a recent study looking into AMD patients’ awareness of nutritional factors, which identified a lack of understanding of the link between AMD and nutrition amongst AMD patients; more than half of the surveyed patients (n = 158) did not think they received enough information about nutrition and it was also demonstrated that AMD patients are not consuming recommended levels of nutrients (Stevens *et al.*, 2014).

Participants reported that the Macular Society, their ophthalmologist, members of their family and the internet are the prime sources to which they turn for information about their condition. When asked their opinion on whether AMD could be prevented by lifestyle choices, such as diet, responses were equally split between “yes”, “no” and “*not at our age*”: this would largely seem to mirror their current assessment of the availability of information pertaining to the link between nutrition and their eye health.

Technology use reported by our participants in this phase is comparable to our findings during our knowledge elicitation phase (Chapter 3), with mobile phones reported as the most commonly used technology (6 participants) followed by laptops (1 participant) and Kindles™ (1 participant); 3 participants reported no use of technology of any kind, but were not asked to elaborate on their interpretation of ‘technology’ to substantiate their claims.

Finally, participants’ views on technology use, and technology in general, were divided: some were clearly uncertain as to the benefits of use of technology; some were intrigued to learn what technology could offer (or do for) them; others, however, believed technology was “*too advanced*” for the older generation, but when asked to elaborate on their thinking in this regard the majority struggled to articulate *why* they held that belief. As suggested by one participant, it is likely a result of lack of knowledge and perhaps even fear:

“But hasn’t it [technology] gone too far for us to catch-up? I wouldn’t even know how to switch some of those things on, so many confusing options.”

Our participants’ views on technology seem to corroborate those reported by Goddard and Nicolle (2012) which highlighted the fact older adults’ hesitance to use technology is founded on the assumption that such technologies are not designed appropriately for their age group. Encouragingly, however, these initial, more negative views of technology were considerably abated – i.e., not echoed during the post-trial interviews – after participants had had the opportunity to *actually* use ‘technology’ (as discussed in the following subsection).

7.2.2.2 Application Usage

During the course of this phase there was unfortunately some unavoidable (and anticipated) participant attrition, amounting to three participants in total. One participant (P9) was hospitalised and could not, therefore, continue with the study (the researcher visited her daughter to collect her device). Another participant (P7) engaged with the week-long study but declined further involvement on the basis that he was intrinsically averse to food and technology in general, as exemplified in the following quotes:

“You are not going to be pleased with me. [...] I can’t deal with this. I would maybe try if you had a talking one. I hate cooking! My brother makes some [food] and I freeze but I hate it. I actually don’t like food, and this is all about food.”

“I can do it with you but then I go home and it virtually goes blank [...] I mean you can see what sort of phone I have got and I cannot even raise the bar [showing an old phone] I mean you could take this back to the museum [laughing]. It’s like saying to me look I am going send you a text will you send me a text back? And I would say “No”, if you want to talk to me phone up and talk.”

When asked what could be done to encourage people like himself to benefit from technology use, the participant explained:

“I like inventing things. Everybody is technology minded but who is doing the manual things? For younger people it’s great, nothing is difficult, it’s dead easy; for an elderly [person] you need a talking one I think. People who overcome [...] problems – they probably have lots of time and nothing else to do, but I can’t waste any more time on this [...] I don’t like using machines – I like doing things by hands and I hate food, it takes too much time: I am a workaholic.”

When asked about particular difficulties with the tablet/application, the participant explained that he just could not “*get the thing working properly*”. The researcher then noticed that the tablet was out of battery, and raised the issue with the participant, attempting to explain why the tablet was not “*working properly*”, but the participant was adamant he could not benefit from the application and, thus, declined to participate in the longitudinal study. This participant epitomises a proportion of older adults who are simply not interested in using technology, especially when equating the use of technology as a task or activity akin to their daily tasks and hobbies as opposed to a valuable assistive tool/solution; this outlook of “*not being interested*” or “*having no need*” is a recurrent reason for the lack of technology use and adoption amongst older adults (Selwyn *et al.*, 2003, p.376).

The final participant (P8) who had to withdraw from the study provided some important insight into, and further awareness of, the needs of people with worst case AMD who have to rely on magnifiers for reading. During the end-point visit, the participant explained to the researcher that she was incapable of using the device because a new magnifier she was prescribed to use was interacting with the device and “*changing*” the screens, making it rather troublesome to use the application. It turned out that this was because she had to hold

the magnifier very close on the screen to read through it, and this was triggering input to the device, ultimately resulting in screen changes. She explained:

"When I touch with this [showing the magnifier] it changes everything. I keep saying [to] my grandchildren "please do it for me". I hate myself for failing it. As long as you know I have really tried, it's just that this thing touches it and it disappears, and makes everything really hard for me."

The participant was obviously saddened and frustrated that she could not continue with the study: secondary to her concern about disappointing the researcher, however, was the fact that her perception of her own failure to complete the study seemed to substantiate her constant fear of how progression of AMD would likely begin to have more severe "control" over her life over time. On a more positive note, the outcome was that she was (prompted by her participation in the study) determined to fight against the impact AMD was having on her life and to take full advantage of the opportunity:

"I will tell you one thing, because how hard I have tried for this thing I have got sky TV and all that recording thing and I have never used it. [...] So this has forced me...and what I'm telling you now Lilit is the honest truth, it has forced me trying to learn so hard to learn how to record it, and not only to record it but also to play and delete. That's how hard I have tried and it forced me to do something about this AMD condition. [...] I am so proud and grateful for it. It might sound stupid, but by taking technology I managed this [pointing at her eyes] and that [pointing to the tablet] beat me, but the TV didn't. [...] So I don't have to think...so I know I am not bloody stupid but just blind. [...] I know what the problem was and it was frustrating, and it's a point you need to know but it has made me stronger and I have forced myself to learn things and to try things and not to let AMD impact my life."

The participant was reassured that her feedback was vital to the future of the application for people with similar stages of AMD. When asked why she did not contact the researcher sooner to explain her troubles, she explained:

"I enjoyed it so much when you were showing me how it worked, and it was a good diet thing. Also with AMD, I know because I came through it for 14 years, what you would get [is] people who heard they just have the disease they would go on this [the tablet] to help them, I know I would, so I really wanted to help. I just wanted you to know I have really tried, really."

It is important to note that P8 was a key member of the prior phases leading up to this phase of the research – that is, she was involved in the knowledge elicitation activities and the participatory design to create the prototype. As such, the issue of use of screen magnifiers had been considered during the design process but it would seem that its actual use in reality

was more problematic than anticipated; this is likely because of the fact that we largely relied on paper prototypes during the sessions to evaluate the UI design, and hence did not encounter similar problems when using magnifiers. While participants did experiment with tablet devices and mobile phones during our knowledge elicitation and PD sessions, it was only the continued use of the device with a magnifier for a longer period that identified this constraint. Furthermore, this participant also took part in the in-home observation study (Chapter 3), but because she was a non-technology user, she was not observed using technology (and hence the use of the magnifier with technology) during the study. Thus, these findings are illustrative of the real value of field studies of technology with its intended user group in terms of uncovering issues that would otherwise have remained obscured.

Of the remaining 6 participants who all agreed to continue into the longitudinal study, two reported very little (but understandable) engagement with the application – one participant's health had deteriorated and she was hospitalised for a few days during the study week and the other participant had suffered the loss of a family member and so had stopped using the application while she was away from home. Both participants were enthusiastic and indeed hopeful about the prospect of using the application for a longer period, as exemplified in the following quote from one of the participants:

“That’s just what I need. I am so fed up with all the reading and watching TV. I am surprised how easy it [the application] is to use. It will give me something to look forward to; I am just disgusted with myself when I couldn’t do it for the few days when I was unwell.”

The remaining 4 participants had each used the application for 5.5 days on average. One participant reported no issues with the tablet; she was thankful for the opportunity and eager to continue with the study, as outlined below:

“Thank you Lilit for opening my eyes. I loved it. I love the idea, it’s probably the way you have explained, but it’s so rewarding.”

The other 3 participants reported similar positive experiences, but had contacted the researcher during the initial days of the study to request help with the device/application. Since participants had trouble articulating over the phone the problems they were experiencing and so the researcher visited all 3 participants at their homes to try and resolve

their issues. Interestingly, most of the problems that participants were encountering were not application related, but were due to hardware issues. One participant was encountering difficulties with the on/off button on the tablet; after every use she was finding it challenging to locate the button on the side, and then she was pressing it with such a force that the tablet was turning off entirely, thus causing unnecessary distress when she had to switch the tablet back on (fully rather than just awakening it from sleep) and log back into her account. The issue was clarified to the participant during the visit, where she also had the opportunity to try turning the device on and off with the researcher present.

The other two participants experienced difficulties with charging their tablets. For both participants, the device was out of charge despite them both believing it was charging. It was observed that the power adapter was not properly connected to the cable in each case and thus not, in fact, charging their respective devices. As above, the issue was clarified with these participants; one participant allocated a dedicated wall socket for charging the device to avoid similar problems in the future. This, similar to findings from our knowledge elicitation activities (Chapter 3), stresses the importance of maintaining support and training in the use of technology for older adult users after deployment of technology.

Reflecting on the issues encountered by the participants it was deemed necessary to create a 'user manual' for all participants. The manual (see Appendix D.5) was created by the researcher to provide an overview of the tablet devices and step-by-step instructions on using the application. Participants who could see the researcher during the week-long study were provided with one to use for the remainder of the study (including the longitudinal study discussed in section 7.3), others were given one for the longitudinal study.

None of the participants used the device for anything other than the application, except for one participant who unintentionally "*opened Google*" when trying launch the application. All participants used the application to merely record their intake of food and did not make much use of its other available functions (e.g., checking recommendations or taking notes). This

was primarily for the reason that most participants assumed “*experimenting*” with the device/app did not include using any other function than recording food. Some were surprised when the researcher asked if they had used the application for anything else other than recording food, with one participant explaining:

“Oh, I thought you wanted me to just test this. I would have loved to see what it would recommend me, but didn’t want to do things I wasn’t supposed to. Silly me, I should have asked.”

While we encouraged participants to use the device and application as it suited them, we refrained from dictating to participants what (i.e., functions/options) and how (i.e., frequency of use) to use the application. We wanted our participants to adopt and settle into a natural and convenient approach to integrating our proposed technology into their lives, in order to fully appreciate if they could continue to use it for a longer period (e.g., for Phase 6). In so doing, we perhaps unduly stressed the food recording (as the main purpose of the application) and did not sufficiently emphasise the importance of the other available functions, such that our participants were fully comfortable exploring those.

Overall, however, the above preliminary results strongly suggest that, with appropriate support and encouragement, technology (appropriately designed) could become an integral part of older adults’ lives.

7.2.3 Summary

While our participants reported difficulties learning to use new technologies, the majority of the problems were not necessarily with the our proposed application, but instead with issues related to other functions of the hardware such as charging the tablet, turning it on and off, and generally locating intended buttons on the device. To overcome these problems, as already noted, further training was provided to all participants (for some this was during this phase, for others additional training was provided during Phase 6), and ‘user manuals’ were created for all participants. Furthermore, the design of Phase 6 was considerate of our deeper appreciation of the fact that continual support and encouragement is necessary for

participants to maintain their motivation to use technology (discussed in the following subsection).

Importantly, the results from this study raised key questions about the acceptability and usability of the application for people who have very limited remaining vision and have to rely on magnifiers for interacting with technology. We have already discussed how, despite being a topic of careful reflection and consideration during the PD of the app itself, the significance of use of screen magnifiers in a practical sense was not fully appreciated until the app was put into real-world use. We had gone to great lengths to try and design a UI that would meet with the visual acuity constraints of our users (and which would encourage visual interaction such that acuity could be monitored over time for disease progression purposes (rather than rely entirely on non-visual interaction styles)). As such, we had deliberately avoided the reliance on speech-based interaction; with hindsight, however, we believe interaction barriers (such as use of screen magnifiers) for individuals with the poorest level of vision could be resolved by incorporating speech recognition technology into the application; hence, although consideration and implementation of this was felt to be outside the scope of this research, it would be an interesting topic for future research.

Despite the aforementioned encounters, however, most of our participants reported positive and rewarding experiences with our application use, and were keen to continue with the follow-up longitudinal study reported below. Encouragingly, while our PD participants were yearning to use the application right from the onset of this study, some of the newly recruited participants were sceptical about the use of technology and the prospect of changing (or monitoring) their diet. By the end of this week-long study, however, all continuing participants reported promising positive changes in their attitudes towards our application to monitor their diet and technology in general.

7.3 Phase 6: Longitudinal Field Evaluation Studies

A longitudinal evaluation study was established to explore the following research questions:

1) Will people use the diary over time?; 2) How do they use the diary?; 3) Are there indications that users improve dietary behaviours in line with advice and recommendations provided by the application?; and 4) Can we identify characteristics of users who are more (or less) likely to adopt/use technology?

Participants in this study consisted of individuals with AMD who had participated in the Phase 5 (week long) study and who voluntarily re-engaged and were willing to continue with this longer study. In total, 6 participants (see Table 7.3 for participants' characteristics) were re-enrolled in the study with a gender split of 4 women and 2 men; participants' ages ranged from 65-89 (mean age 77).

Table 7-3: Overview of study participants' characteristics (participants from previous design phases are highlighted in blue).

| ID | Age | Gender | Experience with Computers | AMD Severity | Number of Years Since Diagnosed |
|----|-----|--------|---------------------------|----------------------------|---------------------------------|
| P1 | 74 | Female | Some | Unknown | 3 |
| P2 | 87 | Female | None | Wet one eye, dry other eye | 10 |
| P3 | 89 | Female | Some | Dry one eye | 8 |
| P4 | 72 | Male | Moderate | Wet both eyes | 4 |
| P5 | 65 | Female | Moderate | Dry one eye | 2 |
| P6 | 73 | Male | Some | Wet one eye | 4 |

7.3.1 Study Protocol

Between five and seven days after completing Phase 5 of the study, the researcher visited participants again at their homes to explain the second phase of the evaluation process. Participants were invited to use the application as part of their daily routine (and not only in their homes) for the subsequent 6 weeks; they were again given the researcher's contact details should they encounter any difficulties, have questions, or want to withdraw from the

study. As before, each participant was provided with the same (as for the previous week long study) mobile device running our diet diary application, and was re-instructed on the use of the application. For this 6-week study, participants were encouraged to use the application in as realistic a manner as possible; they were also encouraged to explore all the functions of the application and, in particular, the recommendations. The device and application were again set up for participants, who then kept the device for the entire duration of the study. On the basis of the findings from the week-long study, 'user manuals' were provided for participants. Consent was obtained as per Phase 5 (see Appendix D.6).

At baseline, and at every 7-10 days (subject to participants' availability), participants were informally interviewed to assess their ongoing experiences with the application. Basic auto-logged data was also downloaded from the participants' devices by the researcher during these visits; logged data included their food recordings and received recommendations. Descriptive (on the basis of small participant numbers) quantitative data analysis was applied to this data, to identify and understand usage patterns and adherence to the dietary recommendations. The data was anonymised via the use of codes (e.g., participant P1).

Time, location and duration of meetings (typically lasting one hour) were agreed with participants on a person-by-person basis; again, participants were encouraged to have a family member/friend present at meetings if they wished. While no compensation was offered for the study, the researcher gave participants a small bunch of flowers as a token of appreciation during most visits.

During the final meeting with each participant, their thoughts on and experience of participating in the study process were briefly reviewed, and a semi-structured interview was conducted to formally identify psychological constructs that may be important in predicting application use and dietary behaviour change over a longer period of use (see Appendix D.8). Data was collected via several instruments, including weekly discussions with participants, auto-logged use of the application, and a final interview.

7.3.2 Application Usage

It is important to note, findings reported in this section are exploratory and should not be interpreted as predictive or generalizable in the statistical sense; these can, however, be explanatory in nature. Over the course of the 6 weeks, an average of 615 AMD-relevant food entries were recorded per participant (see Appendix D.7 for examples of AMD-relevant food definitions and examples as sourced from Macular Society (2015)).

On average, participants recorded 14.6 AMD-relevant food entries per day (including days with no recordings) or 17.4 AMD-relevant food entries per day (excluding days with no recordings) (Figure 7.2). Encouragingly, the average number of days where no food entries were recorded at all was 6.7 per participant (Figure 7.3): reasons for no food entries varied, but participants mentioned feeling unwell, being away from home (e.g., hospital stay or visiting a relative), remembering very late in the day or forgetting altogether as their main reasons for not recording their dietary intake on a given day. It is interesting to note that the male participants' average number of non-use days was 4.5 compared to 7.7 for female participants. This might possibly be attributed to the fact that our female participants were more socially active than their male counterparts; eating out a few times per week, and likely forgetting to record their food consumption as a result.

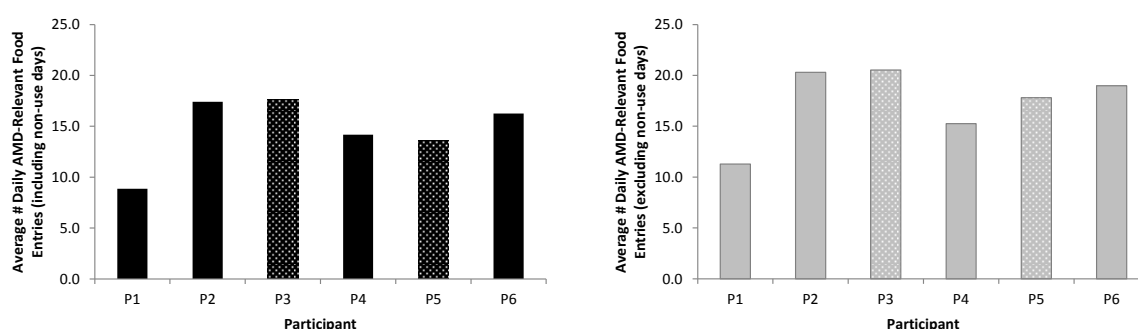


Figure 7-1: Average number of daily AMD-relevant food entries including (left) and excluding (right) non-use days (participants from previous design phases are shown in dotted fill).

As can be seen from Figures 7.2 and 7.3, the largest number of food entries was recorded by participants P2 and P3 (the latter being one of the longest serving contributors to the

research having been involved in the design of the app itself), and the lowest by participant P1. Unexpectedly, it was participant P5 (another of the participatory design participants) who used the diary for the fewest number of days to record food entries. During the final meeting, participant P5 explained that she had been out more often, and thus had not been able to use the device “*as required*” during the final week of the study. She explained that she was apprehensive about taking the device with her to avoid causing any damage to it, despite our encouragement (to all participants) to use the device outside the home setting without worrying about possible damage to the device.

Interestingly, as can be seen from the chart on the right of Figure 7.3, it would appear that number of days’ use is not necessarily a strong predictor of actual use intensity: for example, P4 used the app most regularly but made fewer entries; in contrast, other users may have had more non-use days, but their diet on the days they did record their intake was more AMD-relevant and detailed. Our data does not support deeper inspection of this observation (further research would be required to investigate this more fully), but anecdotally, we suggest that the lack of obvious positive correlation could be a result of poorer diet or the fact that participants were perhaps only using the application for part of the day, and thus not recording their full intake of food. For example, P4 had a restricted diet in terms of variety of food items consumed due to other health concerns, so it may be that he recorded a more limited intake of food on the basis of number of types of foods, but could conceivably have consumed the foods he *did* record in larger quantities. What can, tentatively, be extracted from the observations is that, although participants may not use the app every day, its use is still valuable and (as would appear to be the case as reported later) impacting positively on participants. Perhaps it is unreasonable to expect participants at this age with their range of co-morbidities and other life barriers to use the app any more regularly than we have witnessed? If so, it would appear that their use of the app, when possible, is potentially meaningful and worthwhile.

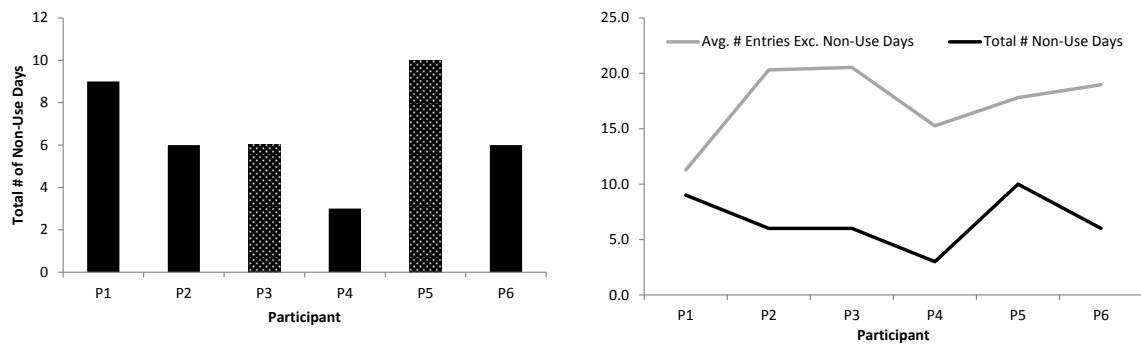


Figure 7-2: Total number of non-use days per participant (left) and comparison of non-use against average number of entries excluding non-use days (right).

Participants' individual use patterns (see Figure 7.4) showed that participants P1 and P2 largely maintained their entry rate across the duration of the study (allowing for fluctuations along the way), with participants P3 - P6 (of which two were our PD participants) increasing their average number of food entries from week 1 to week 6 of the study.

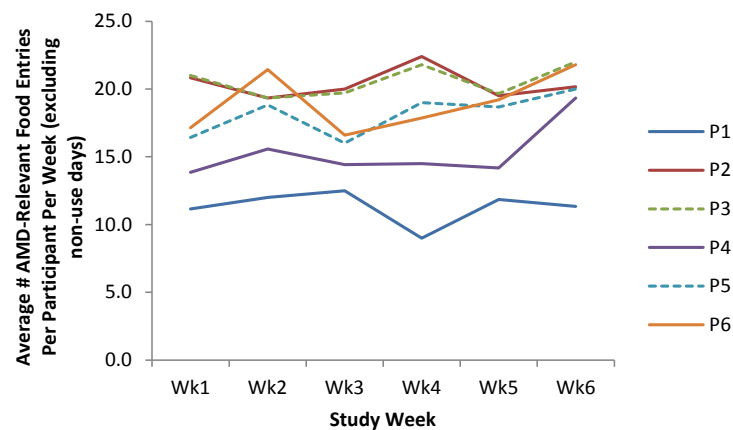


Figure 7-3: Average number of AMD-relevant food entries recorded over the course of the 6 weeks according to participant (participants from previous design phases are shown using a dotted line).

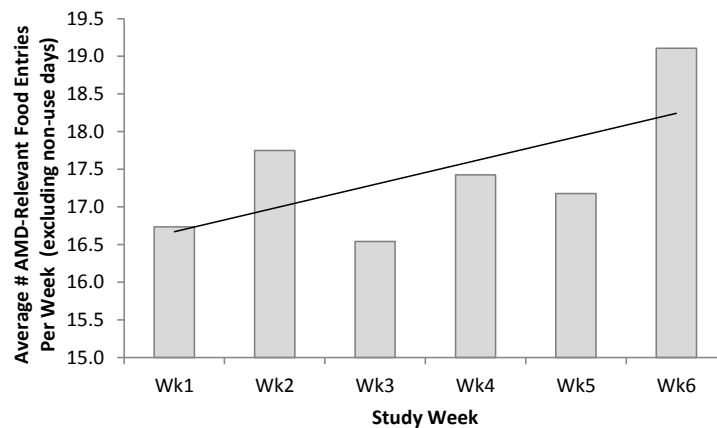


Figure 7-4: Average number of AMD-relevant food entries recorded over the course of the 6 weeks across all participants, showing linear trend line.

No participant dropped their entry rate overall, which is a promising indicator of continued use. In fact, as illustrated in Figure 7.5, results would suggest that, across all participants, there seems to be an increase in the number of AMD-relevant food entries from week 3 to week 6, thus, potentially *adherence* to dietary recommendations (further discussed in section 7.3.4.2). A repeated measures one-way ANOVA test with a Huynh-Feldt correction was conducted to investigate if there was significant (a significance level of $P < 0.05$ was used) improvement in participants' intake of AMD-relevant food items over time. Results were not found to be scientifically significant ($F(5.000, 25.000) = 2.407$, ns). The means and standard deviations are presented in Table 7.4. While the correlation was not significant relative to the standard alpha level of .05, the p-value, however, was less than .10 ($p = .065$). This lack of significant change in the number of AMD-relevant food entries recorded in the current study may be attributed to the following two factors: (1) the relatively small number of subjects taking part in the study; and (2) a more longitudinal studies are required before sufficient cases accrue to give statistically meaningful results. That said, the approaching significance in the reported results (together with participants' reported positive change in their health behaviour (Section 7.3.4.2)) could be interpreted as positive indicators that sustained use of the app for recording dietary intake could lead to improved dietary consumption.

Table 7-4: Means and standard deviations for number of AMD-relevant food entries per week.

| | Mean | Std. Deviation | N |
|-------|---------|----------------|---|
| Week1 | 16.7167 | 3.86648 | 6 |
| Week2 | 17.7333 | 3.37382 | 6 |
| Week3 | 16.5333 | 2.93780 | 6 |
| Week4 | 17.4333 | 5.02262 | 6 |
| Week5 | 17.2000 | 3.31300 | 6 |
| Week6 | 19.1000 | 3.96485 | 6 |

It was, however, not possible to record and therefore determine participants' specific observance of the system's dietary recommendations: i.e., we can't tell if a dietary intake was

a direct consequence of recommendations from the system or something participants would have normally consumed. That said, if we consider the number of recommendations from the system as a proxy for participants' attempt to improve their diet (i.e., fewer recommendations representing stronger conformance with AMD dietary guidelines) then we can identify indicators of the positive impact of the recommendations. Figure 7.6 shows the average number of recommendations made across all participants from week 1 to week 6 of the study: the overlaid trend line suggests a possible reduction in the average number of recommendations, accounting for days of non-use. Results from a repeated measures one-way ANOVA test with a Huynh-Feldt correction also showed a significant (a significance level of $P < 0.05$ was used) effect of time on the number of recommendations made across all participants from week 1 to week 6 of the study, ($F(4.703, 23.513) = 3.847, p = .012$). The means and standard deviations are presented in Table 7.5.

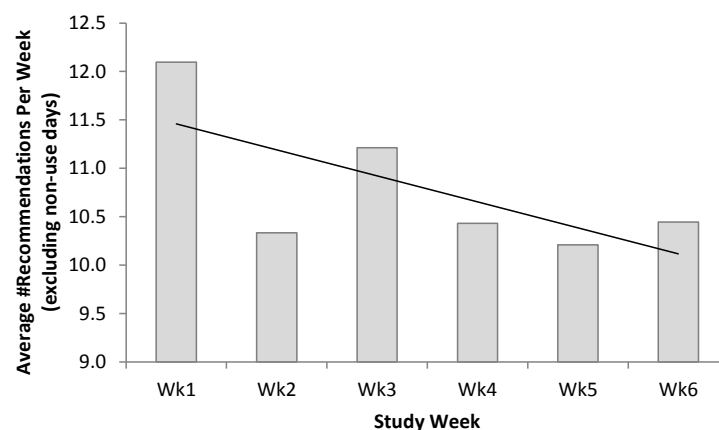


Figure 7-5: Average number of recommendations made over the course of the 6 weeks across all participants, showing linear trend line.

Table 7-5: Means and standard deviations for number of recommendations made per week.

| | Mean | Std. Deviation | N |
|-------|---------|----------------|---|
| Week1 | 11.5500 | 2.54539 | 6 |
| Week2 | 8.7833 | 1.14091 | 6 |
| Week3 | 10.0500 | 1.69086 | 6 |
| Week4 | 8.7167 | 2.25248 | 6 |
| Week5 | 8.8667 | 2.84300 | 6 |
| Week6 | 6.6000 | 2.95703 | 6 |

If we then compare (see Figure 7.7) the average number of recommendations to average number of AMD-relevant food entries (excluding non-use days) per week, we can see divergent trend lines – increasing AMD-relevant food entries against decreasing recommendations. This might *suggest* an overall move towards not just more detailed food recording, but also more appropriate diet (such that fewer recommendations are required).

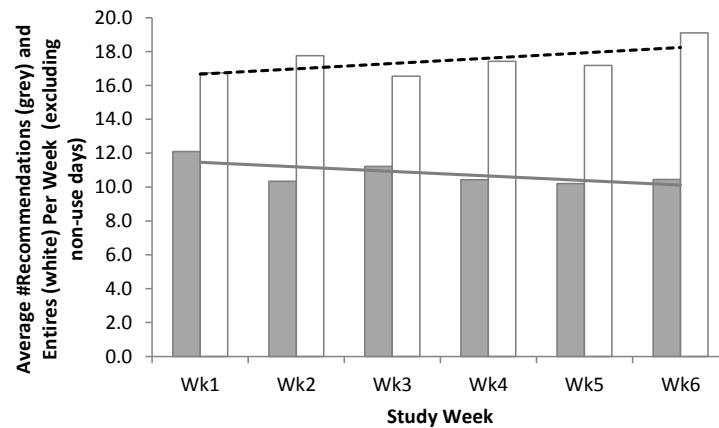


Figure 7-6: Average number of recommendations (grey) made over the course of the 6 weeks compared to average number of AMD-relevant food entries (white) across all participants, showing linear trend lines for each.

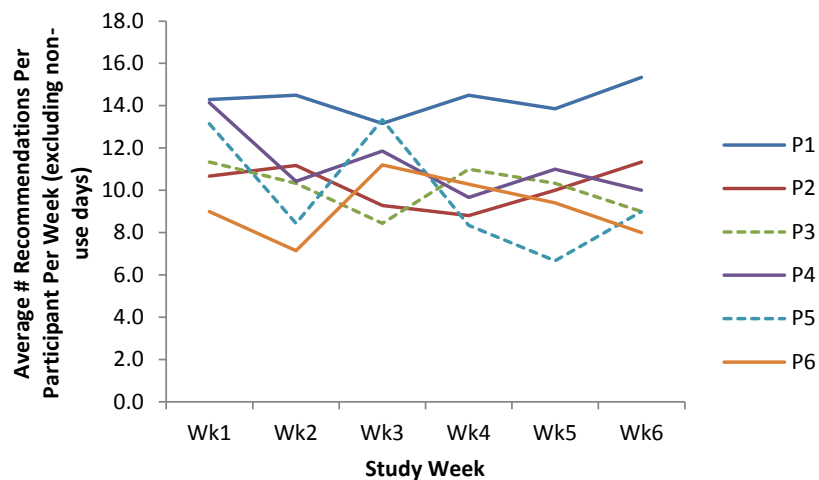


Figure 7-7: Average number of recommendations made over the course of the 6 weeks according to participant (participants from previous design phases are shown using a dotted line).

Figure 7.8 illustrates that, much as might be expected in line with food entries as shown in Figure 7.4, P1 and P2 (who largely maintained their entry rate across the duration of the study) actually saw a slight rise in the number of recommendations from start to end of the study period whereas all other participants (P3 - P6) who increased their average number of food entries from week 1 to week 6 of the study saw a drop in number of recommendations.

These are positive indicators that sustained use of the app for recording dietary intake leads to improved dietary consumption, and hence less requirement for recommendations. The qualitative feedback from participants (see later) would seem to support this proxy-based assessment.

Consider now, as another proxy for effectiveness of the device and associated recommendations, the consumption – both in terms of number and range of AMD-recommended food items – across the 6 weeks of the study. We mapped participants' consumption of AMD 'good foods' according to the quantity and range of potential food types consumed.

Figure 7.9 shows the average number of AMD 'good food' items consumed across all participants from week 1 to week 6 of the study: the overlaid trend line clearly shows maintenance across the 6-week period in terms of the average number of items consumed.

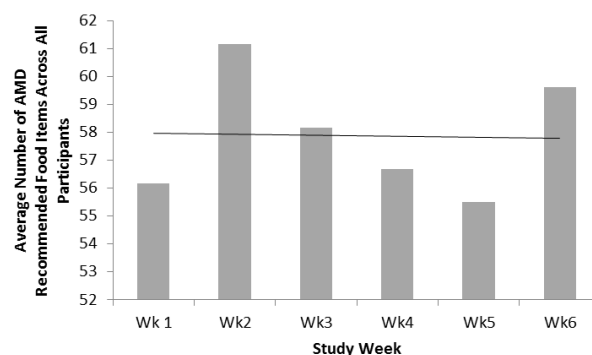


Figure 7-8: Average number of AMD recommended food items consumed per week.

Furthermore, in terms of the *range* or variety of AMD 'good foods' consumed (i.e., the percentage of food items within categories that were consumed – see Figure 7.10) we can see that, on average, participants consumed 100% of the potential food type varieties for Omega 3, 87.2% for ACE food types, 85.7% of superfoods (which we classify as AMD 'good foods' that qualify under 2 or more of the other categories), 63.2% of lutein foods, 58.3% of zeaxanthin foods, and 42.9% of orac foods (note that foods are not mutually exclusive to categories). These numbers suggest that the app is supporting participants in consuming a healthy range of products within categories: qualitative evidence would suggest the

recommendations were encouraging participants to try food types they would not normally have considered.

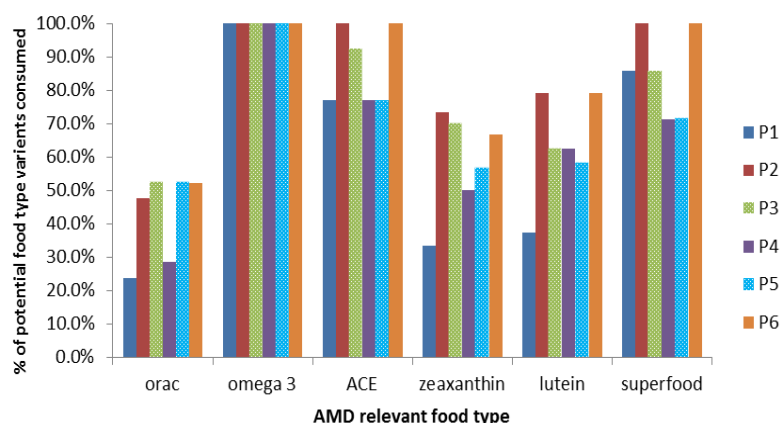


Figure 7-9: Percentage of potential food type variants consumed according to participant.

All participants reported using the “*Progress*” option to view their recommendations and monitor their history of food recorded. In terms of personalising recommendations, only 2 participants recorded ‘disliked’ food items (this was done during the start-point meeting when the device was set up for participants). Another participant refused to take advantage of personalised recommendations as she was “*curious*” to learn what items would be recommended to evaluate her own eating habits: this was an example of participants’ openness to expanding their culinary repertoire on the basis of recommendations. None of the participants used the “*Alterations*” option to change their initial set-up, but two participants reported “*experimenting*” with altering text size and background colour. Finally, 3 participants reported using the “*Notes*” option to record notes.

7.3.3 Perceived Ease of Use

Participants’ main qualifier in terms of the application’s usability and acceptability was that the application was “*easy to use*”, as exemplified in the following quote:

“It was just easy to use, very pleased. Thumbs up.”

Encouragingly, participants with no previous experience with technology found the application easy to use, as suggested in the following quote:

“Once I got the hang of it, it went really well, provided I did not log myself out. I have never used a tablet or a smartphone or a computer before, but this was great, very easy to use indeed.”

Feedback from all participants indicated they found the application less confusing to use than they anticipated would be the case. One participant mentioned keeping a paper diary of his intake of food for other health conditions, and said that using the application for recording intake of food was “*encouraging*” and “*much easier to use*”. He also explained:

“I don’t have to write things down and it records it straight away – Brilliant.”

Interestingly, another participant also compared the application to a paper diary and indicated that ease of use and efficiency are the main advantages of using the diet diary application over the paper diary, explaining:

“It’s certainly easier than writing on a paper. If you’d asked me to write it down, my diet, every day, I might get really bored doing it every day, but this one took only a few minutes to do it, so easy to use. I did forget the other night, but as far as time is concerned it’s very easy to use I didn’t find it tiresome or anything liked that.”

In addition to ease of use, participants also recognised comfort and portability as further advantages of the application, as explained below:

“I just see it as an application that is trying to make an improvement in how people generally think about food, and anything to do with health, and move towards making it easier and easier to deal with. [...] The app is quite easy and takes a very short time: I mean you can even do it sitting in front of the TV, you can use your one hand and can turn it on and off very easily, it’s not bulky, it’s very easy to use.”

A few of the participants admitted that that some effort was required from them to learn how to use the application to start with, but because they were willing to invest time and effort in this activity, they managed to overcome the initial hurdles and enjoyed using the application, as exemplified in the following quotes:

“I found it very easy, no problems at all. At the beginning obviously not so [easy] as I have never used anything of this type before, but once I got used to it, it was great No problems at all.”

“It was fairly easy to use. Yeah once you got the hang of it, it was easy to use.”

“I did find it easy after I understood how the thing worked... at the beginning I thought ‘God I am never gonna be able to use this’. I was really getting myself beat up with that. I was frightened I would do something to the computer but as soon as I got passed that phase, and you explained everything again, that was fine. and I knew how to get back to it, that was the important thing. After I knew how the system worked I did not have any problems.”

Positive comments also applied to the notion of using a tablet as the hardware medium for similar applications, as noted below:

“I did have difficulties to start with but, quite honestly, I think it is easier than computers, because after a few trial and errors I think I have mastered it [laughing]. It was fun and easy to use. Also, you just pick it up so it gives me some kind of notion to buy one like this [referring to the tablet]. It is easy. You can take it with you and I can see everyone using them - my grandchildren. So if you come back by Christmas I might have one.”

Another participant further elaborated:

“Well, if you were somebody like me, who wasn’t into something like technology – I don’t love it, I am never going to love it, but I would say it’s quite convenient to use because 1), the tablet is easy to use, there isn’t too much to do, and I could do it in a very short time, which is at this moment in time quite useful...and plus I lead a very social life so when it comes to a certain time I think right that’s me done, so done everything now I will try to watch TV. So I do not want something that is going to take hours to do, and this was just that – easy to use.”

Participants also commented that it was reassuring and encouraging to know that they could use “*trial and error*” to learn how to use the application by being able to handle errors, with one participant explaining:

“No, I just found it quite easy. When I did something I could take it back, especially when you showed me the bits and bobs, it was really easy.”

Finally, it was reassuring to get our co-designer participants’ approval (with suggested improvements and enhancements – see Table 7.6) on the final design of the application, as indicated below:

“Good! We certainly made the right choices; the only thing I would say is the icons on the tablet side are small. But the whole thing that we set up is great! Can’t fault it, I can’t fault it, so easy to use.”

“Yes, everything we said it was going to be it is, all the options, everything is great!”

It is important to note, that some of the suggested modifications and improvements could also, to some extent, improve the perceived usefulness of the application, which is discussed in the following subsection.

Table 7-6: Participants’ recommended modifications and improvements to the diet diary application prototype.

| Feature | Proposed Modifications/Improvements |
|---------|-------------------------------------|
|---------|-------------------------------------|

| Feature | Proposed Modifications/Improvements |
|--------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Recording intake of food | <ul style="list-style-type: none"> • The app <i>should</i> provide functionality to record intake of food based on users' selected date from the calendar. • The app could benefit from voice control to record intake of food. • The app could use reminder style notifications to encourage intake of food. • The app must include a more comprehensible food database. • The app must remember previous food entries to allow easy selection. |
| Recommendations | <ul style="list-style-type: none"> • The appearance of the recommendations list could be enhanced to make it more appealing. • Images could be used instead of text. • The app could provide personalised messages/tips to support adherence to recommendations. • The app could make recommendations a day in advance to allow for planning. • The app could assist with planning meals by making recipes recommendations. |

7.3.4 Perceived Usefulness

Our thematic analysis uncovered four sub-themes pertaining to the perceived usefulness of the diet diary application as recognised by our participants all of which are discussed in the following subsections: (1) the application raises awareness and facilitates self-monitoring of diet; (2) it encourages positive (diet) behaviour change; (3) it improves memory; and (4) it encourages learning.

7.3.4.1 Increases Awareness & Encourages Self-Monitoring of Diet

Findings from our study revealed that one of the main advantages of the application was its capacity to empower participants to self-monitor their health and thus improve their health and independence. This is particularly important, as studies examining the experience of living with AMD have found that many older adults find it troublesome and upsetting to rely on others (i.e., family members) for help (Wong *et al.*, 2004b) and fear that this potential dependence can lead to unsatisfying consequences (e.g., being placed in nursing homes) (Mogk, 2008). Our participants indicated that the application would heighten their confidence and hopefulness in taking charge of their own health, and thus improve their emotional wellbeing: low mood and a lack of positive outlook are also reported as recurrent consequences of AMD (Stanford *et al.*, 2009), and have been shown to be significantly

associated with poor appetite in older adults (Engel *et al.*, 2011). As one participant explained:

"It [the app] would give you some hope, whereas with this [shows doctor's appointment note] you would just get medically messed with...whereas with this [the app] you would have some hope of directing your own health. It's a self-help. It would only do good and make you feel emotionally really good."

A less frequent but noteworthy sub-theme was the importance of raising participants' awareness about their intake of food and motivating them to take better care of themselves as a result. As one participant explained:

"You are trying to help yourself. It raises your awareness about what you take. It's an eye-opener so [friend] and I could use this. I think it motivates you and I think with our eyes we would be more motivated to use this. But I suppose what it is doing it is helping someone else who will be diagnosed with AMD."

Another participant was surprised to learn how much food he was consuming on a daily basis:

"It was fine, it was interesting. I was surprised I could use it; one thing I was surprised is when I looked at the list of food entered at the end of the day I was quite surprised at how much I had eaten. When you look at the list you think did I consume all this?"

All participants agreed this increased awareness of their nutritional intake was one of the most positive impacts of the application. Most commented that, by only just recording their intake of food and then checking their 'history' of items recorded, the app made them realise how little (or unhealthily) they were eating. It was this self-monitoring of their diet that required them to evaluate and rethink their intake of food, as exemplified in the following quote:

"I eat well now and its only when I scribbled down for this thing [the app] I realised I was eating hardly anything. It's only when I noted down important...because like you said the important issue was the nutrition [...] I was looking at what I had [...] I hardly had any fruit and then I thought well I am only having cereal and a piece of toast and don't have anything constructive with it [...] so I need to do something, haven't I?"

Another participant explained:

"It concentrates your mind as to what you are actually eating and drinking, and when I haven't been drinking enough a couple of days ago I could go back and check and see that I haven't been drinking enough. I got on quite well with this. And so it concentrates your mind on what you are eating and drinking, or what you shouldn't be eating. Yeah it's great, I really enjoyed it."

Participants also reported that as a result of their increased awareness, they felt more determined to monitor and improve their health. As one participant noted:

"I am also determined to eat well to look after myself, so if I eat well and look after myself I can do it, wouldn't it be marvellous."

Participants also thought the application would be informative and beneficial (for monitoring diet) for other older adults with AMD – older adults who might otherwise feel excluded and less motivated to seek information on healthy eating. As one participant explained:

"It's the awareness of the nutrition. It's not good to read in a journal you need to eat the ... the ... the ... the, and I think everybody in my position must feel the same, the Women's or something [referring to the Woman's magazine] might say eat this and that, but then after a few days you gonna throw the thing out and you are left with nothing. There are so many people who live on their own and they don't go out to eat. The nutrition is the most important thing, [...] It's the neglect of yourself you need to tackle."

In effect, participants' feedback indicated that the application encouraged and empowered them to efficiently and more pro-actively manage the diet-related aspects of their condition, as exemplified in the following quote:

"I think if you were diagnosed with AMD, then this app would have made you proactive at least. With this, if you were given this, you would think 'I am taking a proactive approach and doing something for my health'."

These reactions are all reported to increase perceived usefulness, and subsequently acceptance, of self-monitoring technologies (Or *et al.*, 2011) so are promising indicators of the longer term acceptance and success of our app".

7.3.4.2 Positive Behaviour Change

One of the most encouraging realisations to emerge from our findings was our participants' observed positive change in their health behaviour. All participants described positive behaviour changes to various degrees (from drinking more water to generally improving their diet). They reported that their increased awareness (as discussed in the above subsection) of their intake of food motivated them to reconsider and re-evaluate their diet, and led to positive changes in their eating habits. For some, this awareness afforded an explanation for other health concerns and, therefore, offered a prevailing motivating trigger to change (and improve) their diet overall. For instance, one participant explained:

“You know what’s really interesting, since I have been checking my history [app entries] I did not realise how little I was eating, so no wonder I am so weak. So I am determined to improve my diet.”

Another participant further added:

“Oh you are a little genius you are [referring to the app]. I do really work on my nutrition now.”

For some participants the use of the application led to minor changes. As one participant noted:

“I have started drinking more water because of this [the app].”

Other participants, however, affected more substantial changes to their eating habits. For instance, one participant explained:

“Funnily enough I looked, I don’t [eat] enough fruits so when I saw grapes on my recommendation list, I started eating grapes and I shall continue doing so. I get on quite well with grapes and hope to make it a regular thing. I should also eat a lot of fruits I know now that I don’t.”

Another participant further added:

“I tend to have peanuts; it keeps recommending almonds and hazelnuts, so I will change to it, if that’s what they are telling me, it must be good for me.”

Interestingly, some participants have also delved into the nutritional values of the suggested recommendations. This supports claims that older adults are more likely to perceive self-monitoring technologies useful and thus adhere to recommendations when the use of such technologies can improve their healthcare knowledge (Fowles *et al.*, 2004; Ferguson, 2000): in our case, this involved understanding why a particular item of food is being recommended.

As one participant explained:

“Now, the other day I did not realise I did not have zinc, I used to eat bananas but then stopped, so that was a great thing to discover that I do not eat enough zinc.”

Another participant further elaborated:

“Yes I did recommendations, and I did notes, and I could see where it was saying different vitamins I needed. I was having pumpkin seeds because it was recommending it and so I gave a go”

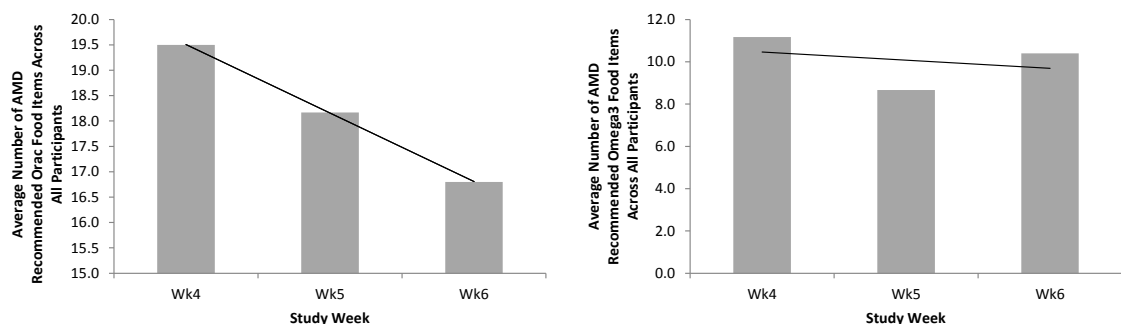
The qualitative findings reported here and in the above subsection suggest that the application was successful in promoting enhanced (eating-related) health behaviour and various degrees of adherence to dietary recommendation. This was primarily because the application increased participants’ awareness about their eating behaviour, encouraged self-

monitoring of their intake of food, and improved their healthcare knowledge. As one participant explained:

“The benefit I found was it made me sit down and list everything I was eating and drinking so it regimented me into thinking logically – ‘right what did I eat today?’ – and reminded me if I did not eat or drink enough, though drinking primarily. So it concentrated my mind on what I was eating or drinking because we never do enough, so it’s a discipline of doing it. I get frustrated when I don’t drink enough and my wife reminds me to go and have a drink so this is great.”

In support of the qualitative findings reported above, we analysed the extent to which participants *actually* altered their food intake of AMD ‘good foods’ across the 6 week study period. Figure 7.9 (above) suggests that we perhaps witnessed an initial ‘novelty’ effect in weeks 1-3, which dropped off thereafter resulting in lower consumption in the middle of the study period, but with ‘good food’ consumption reclaiming some ground by week 6: we suggest, therefore, that the consumption trend in the latter half of the study period is more indicative of realistic and sustainable consumption.

We therefore looked at the trend in participants’ AMD ‘good food’ consumption according to the following AMD-relevant food categories (see Figure 7.11) for the final 3 weeks of the study: orac; omega 3; ACE (vitamin A, C and E); zeaxanthin; lutein; and superfoods (as already mentioned, these are foods that we can classify according to two or more of the previous categories).



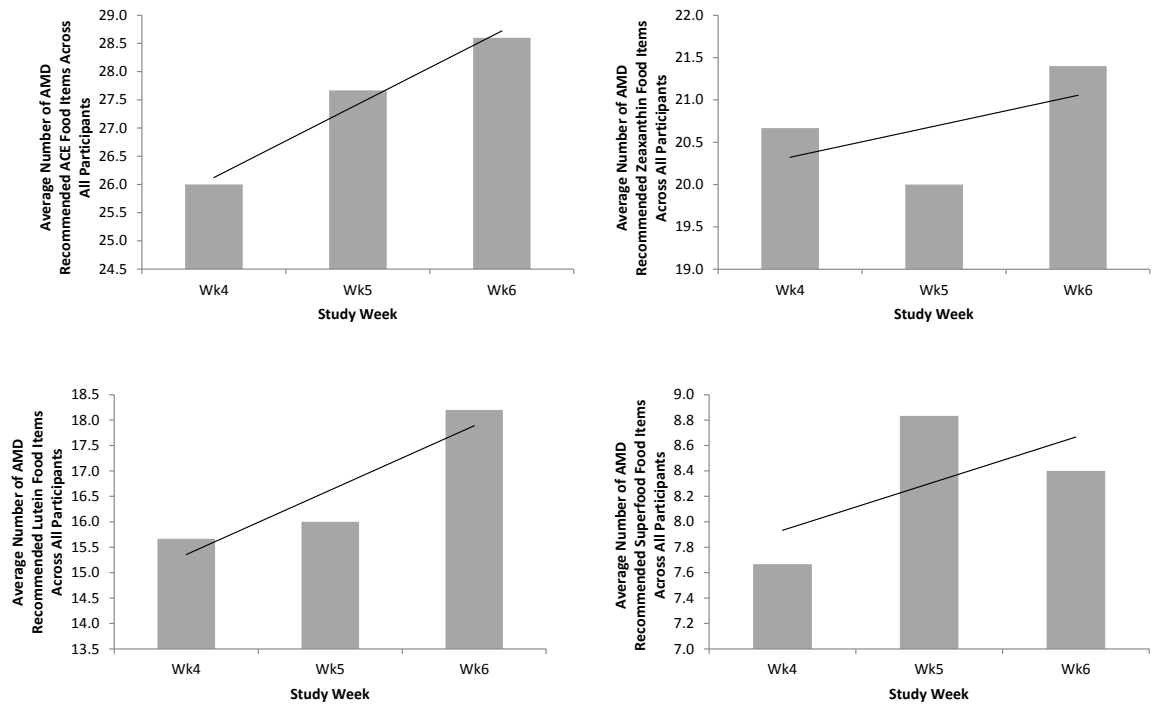


Figure 7-10: Average number of AMD 'good food' items consumed per week across weeks 4-6 according to food category (showing linear trend lines).

With the exception of foods in the orac category (e.g., apples, bananas) and to a very slight extent Omega 3 category (e.g., cheese, meat, milk), results would suggest a slight upturn in the levels of consumption of foods across each of the AMD 'good food' categories as the study progressed following the wearing off of novelty effect. At the level of conjecture, many participants had already achieved a relatively steady state consumption of orac food stuffs (foods like apples and bananas being familiar and consumed frequently across all participants) and perhaps sacrificed some orac food consumption in order to intake some of the other 'good foods' about which they were learning as a result of use of the app. Similarly, although omega 3 foodstuffs saw a very slight drop over the same period, participants were consuming all varieties of omega 3 foods, and as such, may have done some further substitution for the benefit of dietary exploration. Overall, a combination of participants' self-reported adherence to dietary recommendations and dietary change and the recorded evidence illustrated above indicates that positive dietary behaviour change was observed across the participant group, ending up with realistic consumption levels which we would hope to see sustained over time.

7.3.4.3 Improves Memory

An unexpected and very encouraging finding of our study was that the use of the diet diary application appeared to improve participants' memory (an area with which many older adults require assistance (e.g., Maciuszek *et al.*, 2005)) or at least their perception of their own memory. Participants felt that this was primarily because they were required to follow a planned and structured routine to record their intake of food and that this possibly resulted in enhancements to their memory. One participant explained:

"I think you have to have a routine with it, especially if you make your mind up teatime-ish. But I have to tell you it makes wonders to your memory."

Another participant added:

"I think my memory is not as bad as it used to be, you know I think it's improving."

The fact that the application required participants to reflect on and remember their intake of food has also likely contributed to their perceived memory enhancement. As one participant noted:

"It all depended how I felt myself. If I was really well I could remember all the things I had. It wasn't difficult to remember what I ate because it made me think, yes, it made me think I could. At times I would not do it quick and it irritated me – I wanted something simple on my mind, but when my memory clicked I did master it, I thoroughly enjoyed it."

Interestingly, as well as improving their memory, participants also commented that using the diary had *supported* their memory. Participants who used the 'Notes' option found it particularly helpful to record notes and appointments to support their memory. As one participant noted:

"I have all my appointments here, its brilliant, look I have your appointment here and my doctor's one. All the things that I have to remember goes here."

A similar comment was also made by another participant, who suggested that the use of the application has taken the pressure off having to remember things:

"I prefer to do it this way [showing the application], otherwise you can't remember what's in your brain, when the doctor asks you. If you try to remember what you had ... ok you could do it but I don't have to with this [the application]."

Finally, all participants reported taking advantage of the prospect of viewing (and thus recalling) their daily intake of food: all acknowledged it supported them in monitoring their diet, planning ahead, structuring and "*organising*" their "*actions*", all of which have contributed to their self-reported improvement of memory.

7.3.4.4 Increases Motivation to Learn

A further important finding of our study was the increase in our participants' motivation and determination to learn as a result of the confidence gained from using the application. Challenging recent suggestions that low healthcare knowledge amongst participants hinders the acceptance of self-monitoring technologies (Or *et al.*, 2011), findings of our study suggest that older adults are more than willing to invest time and effort on learning about both about their condition and the proposed technology as long as the benefits of such investment are appreciated. Most of our participants reported a keen interest in learning to use the diet diary application (and technology in general), provided they could appreciate the need for such technology, the relevance of it to their lifestyles, and benefits gained from using technology. As one participant explained:

"Because of this I am back to reading heavy stuff, so thank God for it. I am pleased about that and also I rung about joining the computer club I told you [...] but they said they would [enrol] in the new year...but I thought by then I would be more irritable with myself once you take this away. I really should be learning shouldn't I?"

In fact, some participants suggested the opportunity (and challenge) of learning new things is an important advantage of using technology: it was perceived as a means for keeping mentally agile. As one participant explained:

"It's up to you, it's up to you, the choice is yours. You can go out or stay at home and keep twiddling my thumbs. I was busy like you when I was 30 and it does get better. You need something to register, to keep your brain cells busy".

Further, the experience seemed to enhance our participants' social status and changed their outlook on life. Participants reported feeling honoured to be part of the project, and took pride in sharing their experience with friends and family members. Most participants were surprised of their own learning capabilities. As one participant explained:

"People say 'and this lady left school at 14 you know', so I have to self-educate, I can't believe I am saying this."

Other participants have also reported strong desire to learn to use computers, and to take full advantage of the "internet" and their mobile phones. In fact, two participants reported making enquires at local libraries and clubs for courses on using technology. One participant noted:

I hope this [the app] can help me to go back on to the computer. It's like my new toy, I am determined to master it; I will not be defeated. What fascinates me is that you can enter this information feed in [...] I am much more proud of myself because before I would be 'oh I will read a magazine' but now, that is a bigger interest altogether [...] I was thinking that maybe after Christmas going for computer classes so I can go back on to computer. That would be marvellous, so I am determined."

Another participant added:

"It's not difficult, it's a question of it has to click in here [pointing to her head]. I just need to go to a class and be in the same boat as everyone else. I don't mean wonderful brains and all that because it's there, so I really need more classes to get more feedback."

One participant hoped that learning to use technology could improve her independence, as she had to rely on her hairdresser for most technology associated tasks (e.g., booking flights). She explained:

"It's like a God send, absolutely brilliant. When I see my hairdresser she booked everything for me. Yes it's the fact that I feel inadequate without technology, so maybe I can do all this things."

Our participants acknowledged that some effort was required from them to learn how to use the diet diary to start with, but they also recognised the sense of accomplishment and enjoyment felt when challenges and fears were conquered, as highlighted in the following quote:

"Oh the first couple of days to get struggling but no difficulties at all, soon I could get myself out of troubles, and that was a great feeling, indeed."

Similar to our findings from the PD activities reported in Chapter 4, our participants were surprised to learn and enjoy something they previously did not understand. Importantly, participants also learned a great deal about healthy lifestyle and their own eating habits.

7.3.5 Other Factors Influencing Participants' Experience

In addition to the ease of use of the diet diary application and its perceived usefulness for our participants, we identified other factors influencing and contributing to participants' experience of using technology. These factors include participants' determination and motivation, pride in taking part in the study, and showing interest in others, as discussed in the following subsections.

7.3.5.1 Determination and Motivation

Findings from our study suggest that personal level of motivation and determination are significant factors influencing participants' experience of using (and adopting) technology. A study looking at the experience of living with AMD found that independence was one of the most negatively impacted aspects associated with participants' quality of life (Mitchell *et al.*, 2005). Our participants cited an array of motivations to use the application (e.g., to take charge of their health, to improve their diet, to keep their brain cells active, to stay connected to the younger generation, etc.) but, more importantly, they were determined to improve their independence and quality of life. Most participants were determined to use the application, and suggested it provided a sense of being independent and able to do things for themselves: One participant explained:

"So if anyone says 'oh it's going to take me hours', once you get used to it takes no longer than that. You have to be determined if you want to be independent and all that. I would say to people, 'Look don't panic about it'. Once you get used to it, it takes no more than ten minutes to do it."

One participant explained how she was determined to "*master*" the application, so she could improve her health and wellbeing to be there for her grandchildren. She acknowledged that improved diet might have little impact on AMD at her stage of life, but hoped that it would improve her general health. Further, she hoped she would set an example to her grandchildren that "*a little determination goes a long way*", and motivate them to aim higher (just like she was doing at her late stage of life). She recalled how engaging in conversations with herself (pretending to be the researcher) helped her to overcome challenges and not to "*give up*". She recalled:

"Oh I don't find it difficult to use, I just think 'be patient, don't lose the plot [the researcher] would say'. As I say, I have been into Google – it can be done, it can be sorted out – just don't panic – keep going!"

Another participant, who had early stage AMD, explained that she was determined to use the application in an attempt to slow down the rate of her degeneration. Similar to other participants, she was also determined to contribute to a research project that "*could benefit her children*". Besides this, she was also appointed as a secretary for a local AMD club and felt further motivated to help people like her. As she explained:

“It depends how open minded you are with technology. Really I suppose we all have different motivations. Because I am secretary for AMD club, now I have got an investment in this in that we need something like this to help people, it’s the biggest cause of visual impairment here in the UK.”

One participant thought she had never really challenged herself, but she was determined to persevere and make the researcher “*proud*”. She explained that taking part in the project had changed her outlook of life and motivated her to think more positively. She described that the researcher’s confidence and faith in her capabilities gave her the determination necessary to improve her diet (at least for the duration of the project). As she elaborated:

“Technology is a great thing, and it is very important to me, because you [the researcher] believed in me, so you must see something in me, and because I did have an enquiring mind [...] but I will get back on that again, I know I will, I have to remind myself that I can eat healthy even if it is just for this project.”

Similarly, another participant had also considered the researcher’s expectations as outlined below:

“I’m getting on alright [with the tablet] but not good enough for me. I have high expectations of myself [laughing] and I think you have as well high expectations.”

Not surprisingly perhaps, our co-designer participants were more determined to succeed, not to simply improve their diet and health, but also to fulfil their commitment to the project or, as one of the participants said, “*to see the project through*”. Such participants noted that being part of the project from the initial stages of it and contributing to the design activities made them more determined to use the application and adhere to the recommendations.

7.3.5.2 Pride in Taking Part in the Project

Our participants spoke highly of their involvement and took pride in being part of the project. All participants truly appreciated the opportunity to be part of the project and did not merely view it as a service to the researcher, but an opportunity to contribute to something of “*great importance*” that would help the future generations and others like them. As one participant noted:

“The younger people who are going to use this [the app] the ophthalmologist will say it’s in your hands and of you go, go and use this. They perfected this camera that will show you have AMD, so after that they can use this application to improve their diet. Pioneers we are, pioneers.”

Two participants asked to keep all project-related documents as evidence of their involvement; they were keen to share their achievement with friends and family. Similarly, they took pride in identifying issues and suggesting solutions to improve the application. Some participants noted their intake of food or identified issues/solutions on paper and discussed their notes with the researcher during their meetings (see Appendix D.9 for some examples). They liked the fact that the “*young*” researcher was listening to their suggestions and was appreciative of their efforts to help with the project. To highlight the importance of their contributions, the researcher always offered to take away participants’ notes of future enhancements for the application. One participant suggested:

“I will keep documents [project related] to show people what I have done, and you can keep mine if it’s any good for you.”

During the course of the evaluation study, the researcher attended two conferences, about which the participants were informed for scheduling purposes. The researcher explained to participants the aim and purpose of such academic conferences (i.e., presenting research papers), which seemed to further inspire our participants and highlight the importance of their contribution. As one participant noted:

“I don’t think I have ever felt so proud. Well done bright lady. Now I am going to do whatever it takes, especially because it is your PhD project. I am baffling with science. Will you put my name on your paper [laughing]?”

One participant, whose son was an ophthalmologist, said the entire family was very proud of her. She was also one of our co-designers of the application and thus had been involved in the project from the very early stages. She noted that the family had commented on the positive influence that her involvement in the study was having on her: the family had thought she was “*full of life*” and her outlook on life had changed. She further elaborated that her grandchildren had started asking her for help with their college work, because their grandmother was “*collaborating with scientists from the University*”. On numerous occasions she also stated:

“My son is an ophthalmologist, and he is so proud of me and asks when my name is going to appear on one of your articles.”

During one of the final meetings, another participant (who was also a co-designer) invited her daughter along, who requested to see the researcher to thank her personally for the “joy” and “pride” that participating in the project had given her mother. She noted:

“This project is the best thing that has happened to mum. She talks about this everywhere we go. I think everyone in the family knows you [the researcher] by now. She loves going on and on about you and this project, even at my son’s wedding. Thank you for being so kind to her, you have done some wonders.”

Participants who had no prior experience with computers were particularly proud of their involvement and admitted to taking pride in learning how to use technology and solving technology-related problems. As one participant explained:

“Oh I liked it! It was an achievement I thought, because I never used computers or tablets of any description before you know, I wasn’t too adventures with it ... But I got Google, which was great. It was dangerous, but I loved it!”

Another one added:

“I found this fascinating, to be part of this and when things worked for me. It’s a shame a lot of things happened – lots of funerals and other sad things – but it has been a remarkable experience.”

Finally, some of our participants suggested that an “Achievements Certificate” would be appreciated to acknowledge their contributions, but also to show others as proof of their involvement and achievement (this is further discussed in Chapter 8).

7.3.5.3 Showing Interest in Others

An interesting theme to arise from this study was the extent to which participants showed interest in others and considered how they (e.g., the future generations or others like them) would benefit from the diet diary application. Participants who were members of the local AMD group (or other similar clubs for older adults) were keen to share their experience and gained knowledge with others in order to help them with coping with AMD. Participants maintained that being mindful of the range of opportunities that exist to support people with AMD is reassuring: it is encouraging to know that there are people/organisations interested in providing help. One participant explained:

“I have talked about this project with other members [from AMD club] and there are a lot of them interested in taking part; they can talk to me [laughing], I am part of the University trying to help.”

Indeed, this notion of helping others was an important motivating factor, as exemplified in the following quote:

“If you don’t do it for you, do it for the community!”

Some participants took a more proactive approach in helping others and shared their recommendations with their friends and families. While for many participants this was done orally during conversations, one participant went to great lengths noting down and distributing his recommendations to his circle of friends. The participant recognised that the recommendations were personalised, centred on his intake of food, but suggested that they provide a precise indication of the type of nutrition recommended for AMD in general. As before, he also noted that it was comforting to know that there is help available. He recalled:

“There are a couple people that I know would find this really useful who aren’t really eating healthy so this would concentrate their mind. I had lots of people asking me how this was working, what it was telling me, and what recommendations I was receiving. I even wrote down some of it [recommended food] and handed it out to my friends and they said they would like something like this too. It’s this idea that something is being done...it’s comforting to know, the main thing they liked is that it gives recommendations they can eat, so it’s very encouraging to receive recommendations, it gives them a feel, so yes my friends really liked it.”

Most of our participants acknowledged that the diet diary was of little direct value to *their* AMD given their advanced stage of AMD progression (although it was perceived as beneficial to their overall health), but were keen to identify means by which to help future generations avoid the vision loss they had endured. This understanding also helped many of our participants to overcome challenges along the way. As one participant noted:

“So it takes my ignorance for somebody to improve, I can live with that.”

Similar to findings from our PD activities (Chapter 4), some participants suggested that comparing performance (in terms of technology use and adherence to the dietary recommendations) and sharing their experience with a circle of friends and relatives, who also used the application, could be motivational and would create a social support necessary to continue with the use of the application. As one participant noted:

“I think also having other friends who use it if you met or if you all were part of the macula meeting, then you could use part of the meeting to discuss how you got on with it and your progress and so on. You could actually speak to others about your progress. Or involve people who would suggest recipes to cook [...]”.

Important to note, participants did not suggest online sharing; instead, they referred to sharing outside the technology itself, where they have control over the type and frequency of information shared (other studies have also identified control of information sharing as an important factor to consider when designing social networking sites for older adults (Gibson *et al.*, 2010)).

7.3.6 Participants' Post Study Reflections

As already noted, during the final meeting with each participant, we informally reviewed their thoughts on and experience of participating in the study and using the application in an attempt to identify psychological constructs that may be important in predicting application use and dietary behaviour change over a longer period of use.

Discussions during these meetings were largely structured around the “*Theory of Planned Behaviour*” (Ajzen, 1991), which suggests that a user’s behaviour (e.g., use or abandonment of technology) is guided by three kinds of consideration. The first of these is *Behavioural Beliefs* – beliefs about the likely consequences of the behaviour (e.g., the user’s motivation or conscious decision to use (or reject) a particular type of technology as discussed during Phase 5 of our study). These attitudes/beliefs were interrogated again for this part of the study, once the users had the opportunity to *actually* use the ‘technology’, to see if such use had changed their motivations/opinions.

Second, we have *Normative Beliefs* – it is suggested that subjective norms and pressures from others (i.e., friends, family members, etc.) can influence users’ intentions/motivation to use (or abandon) technology (e.g., do users believe people around them would (dis)approve their use of the diet diary?). Finally, *Control Beliefs* refers to whether users’ levels of access to necessary resources and opportunities may facilitate (or impede) their use (or abandonment) of technology (e.g., are there any factors or circumstances that could make it easier (or harder) for our participants to use the technology or to follow the dietary

recommendations?) (Conner and Norman, 2005). The following subsections are structured around these three suggested considerations.

7.3.6.1 Behavioural Beliefs: Participants' Attitudes and Beliefs

Encouragingly, as already noted, our participants' initial, more negative, views of technology were not echoed during the post-trial interviews (after participants had the opportunity to actually use our technology). All participants recognised potential benefits of use of technology (or at least assistive technology). Participants noted *"keeping in touch"*, *"changing outlook of life"*, *"keeping brain active"*, *"staying in touch with the younger generation"*, *"improving independence and quality of life"*, *"making life easier"* as some of the main advantages of (assistive) technology use. As one participant, who was particularly ignorant of technology at the beginning of the study, explained:

"Well it's very good for my brain. [...] It's technology that I need to get back to living, you know. Technology is very important – yes, woman, this is coming from me, can you believe that? [...] Everybody has now got phones – two and three phones. And I have been surviving, yes merely surviving, without it."

Another participant declared:

"Technology is a great thing, and it is very important to me, because I did have an enquiring mind, but I will get back on that again."

When asked about the advantages/disadvantages of using the diet diary in particular, participants identified monitoring their diet and benefiting their eyesight as the main advantages; encouragingly, they could not suggest any disadvantages of using the application. As one participant noted:

"All I am doing is entering food, and it is benefiting me and my condition, so I cannot think of any disadvantages."

Another participant further elaborated:

"It is going to benefit my problem. I didn't find it difficult at all, in fact, I quite enjoyed it. I do not see disadvantages at all, I could not fault it."

When asked what comes to mind when they think about the diet diary and following the recommendations, most recognised it was *"assistance towards healthy eating and healthy lifestyle"*; others argued it was a *"glimpse of hope that things are being done to cure and prevent AMD"* – a condition that our participants thought would hinder their use of

technology. Their support calls for more careful consideration of users' attitudes towards both technology and their own disability, as such attitudes often influence users' technology acceptance and use (Frank Lopresti *et al.*, 2004; Hwang, 2012).

As already noted, in terms of following dietary recommendations, reassuringly all our participants expressed interest in changing (or monitoring at the very least) their diet to various degrees. They acknowledged how recording their intake of food has encouraged them to reassess their diet. This is an encouraging and positive change in our participants' attitudes, as less than half (44%) had expressed interest in changing their diet when asked during the pre-trial interview. As above, this also highlights the positive impact that actual use of technology can have on participants. As one of the participants (who had only participated in the evaluation phases) elucidated:

"It was good. It was interesting, and it gives you help and feedback, which is great. I really did not think I would find it this informative. It was actually fun to do, because it concentrated your mind on what you put in. So, yes, fascinating bit of technology and yet so simple to use."

The above is clear evidence of the positive impact that *actual* use of technology had on our participant (in terms of *attitude* towards technology use): this participant was initially uncertain as to the benefits of such use, and believed technology was "*too advanced*" for the older generation. This highlights the importance of introducing technology to older adults under facilitating and sympathetic conditions; the right deployment approach based on provision of supportive guidance can encourage and motivate older adults to learn how to use technologies using trial and error methods (Barnard *et al.*, 2013).

7.3.6.2 Subjective Norms and Social Pressures

As noted, it is suggested that subjective norms and pressures from others can influence users' intentions/motivation to use (or abandon) technology. It is further argued that this is particularly pertinent amongst older adults, whose intention to use technology is found to be significantly influenced by the perceptions of others' (e.g., Sun *et al.*, 2013). Results from our study, however, do not fully support such claims; discussions with our participants suggest

they are confident in their own decision making, and while they are aware of the opinions of others, such opinions did not concern them nor influence *their* intentions to use technology. That said, our participants would appear to have largely been exposed to positive external opinions – a greater negative influence might have seen different results in this regard.

As already discussed, our participants took pride in being part of the project and indicated that the people around also spoke highly of their involvement – this is particularly true for our PD participants who contributed to the design of the application. When asked to consider *people* who would approve of their use of the diet diary, most participants considered members of their family; one participant (who only contributed to the evaluation phases of our research) identified a friend and her friend's family (this participant had very little contact with her relatives, who lived in a different city to her, which could explain why she did not mention members of her family). As she explained:

“Oh yes, my best friend is very encouraging and her daughter. So I will become competent.”

Nevertheless, the participant did not consider their opinion as influencing her motivation to use the application (despite the suggestion to this effect in her quote), and insisted that ease of use and the benefits gained from using the application were her main motivational factors.

Another participant mentioned discussing the project and the application with her audiologist and other healthcare workers; while she said some were pleased for her, she was also very adamant that she was determined to succeed “*with or without other peoples’ subjective opinions*”. This participant was one of the PD participants, and was particularly proud of her achievement. On one occasion, she recalled taking her device with her during one of her routine appointments with her ophthalmologist, but was “*surprised*” to learn the ophthalmologist wasn’t interested in the project. The participant maintained the ophthalmologist’s “*ignorance*” did not affect her personally, but she did acknowledge that healthcare professionals *can* and *should* encourage older adults who are more “*fragile*” and “*against*” technology to take full advantage of assistive technologies. Interestingly, consistent

with our participant's recommendation, it is reported that subjective norms (e.g., healthcare professionals' opinions) are significant factors in the context of consumer health technology (Sun *et al.*, 2013).

Participants who thought their families would approve of them using the application explained:

"I am sure my daughter would [approve]. She works for the NHS, and is very into healthy eating. My son is a doctor, so I have a lot of people who would be interested to see how my diet works."

Another participant added:

"My wife would be quite happy, knowing that I monitor what I eat. I think she would even give it a go, but she would never stop me from using it."

In fact all, our participants were determined that subjective norms or social pressure could not influence their intention to use technology; some actually failed to think of people around them who could possibly disapprove of them using the diet diary. Other participants only speculated that people might have reservations because of their age (a primary social category (Blaine, 2012)) and stereotypes of older adults. As one participant explained:

"Oh, I think there will be people, who would say 'you silly old woman taking something like this at your old age, leave it to younger people'. But it depends what is in your brain, what is in your mind. I haven't come across people like that, but some could think 'what is she doing?' Why can't she just sit and knit?'. I find it challenging [...] and proving to other people that I can do it, yes!"

Another participant added:

"Well, I suppose there are people who think once you get to a certain age, why do you even bother [with] it? They think, 'shouldn't she be sitting down and read books?' No!"

Finally, when asked who they think would most benefit from using the diet diary, participants were unified in their responses: all acknowledged that, while *they* (and others like them) would benefit from monitoring their diet and improving their general health, it is the younger generation that will take full advantage of the application in terms of slowing down their rate of degeneration of AMD, which, yet again, suggests that the goal of the app has some resonance with its intended user group. As one participant explained:

"I would think [if] someone has been told they have eye problems and they are young, it is in their best interest to get involved in this, because the

recommendations are going to tell you what you need and what you do not need. If an optician told my grandchild they had problems, I would tell them, go and get involved, it is in their best interest.”

Another participant was similarly hopeful that younger members of her family, and the younger generation on the whole, could benefit from the application. She explained:

“Well, people coming through, probably my family. I mean I have got macula, and it may be that it is hereditary, so my children might be coming through with it. If it will benefit them at the early stage, if they are told you have got macula, and here are some aids to help you. So, yes, the younger generation.”

Overall, while some studies suggest a strong relationship between social influence and behavioural intention for older adults (Venkatesh *et al.*, 2012), a salient understanding to emerge from our observations is that our participants are not necessarily reliant on others’ suggestions and expectations for their decision-making. In fact, in our case, it could be argued that subjective norms and social pressure have proven to be less influential than perceived usefulness (i.e., helping younger generations) in terms of colouring users’ intentions to use the technology.

7.3.6.3 Control Factors Influencing Participants’ Use of the Application

Perceived behavioural controls describe the potential conditions which can be derived from both *internal* and *external* factors that constrain or facilitate the use of technology (Ajzen, 1991). External control is concerned with the extent to which individuals have adequate external *resources* to use technology: in our case, for instance, this could include participants’ financial capacity to purchase mobile devices or follow dietary recommendations. Internal control, on the other hand, relates to the extent to which individuals’ own abilities sanction them to perform a behaviour (i.e., use of the diet diary or following the recommendations) (Yang and Farn, 2009): in our case, for instance, we learned from our PD activities (Chapter 5) that the majority of older adults (with AMD) also have other health concerns (often as a consequence of their age) that could hinder or impact their use of technology; similarly, people with cognitive disabilities also often have additional physical and sensory limitations that could affect their ability to use technology (Frank Lopresti *et al.*, 2004).

Within the context of our research, as discovered during Phase 5 (Section 7.2.2.1) of the study, only 33% of participants cited external controls, such as cost of food, as likely factors affecting their intake of food (thus following recommendations); others were more concerned with internal factors such as their preferences or ability to prepare food. When asked the same question again during our end-point interviews, only 2 of the same participants suggested cost as an important factor. One participant, who was suffering from ill health, remained concerned that her ability to prepare food could impact her use of the diet diary. Others suggested their knowledge (or lack of it) about healthy eating as the prime factor impacting their intake of food; this again highlights the importance of informing and advising participants about the benefits of using technology.

When asked if they could think of any factors or circumstance that would enable or make it easier for them to use the application, all our participants suggested that existing ease of use (as discussed in section 7.4.3) of the application was sufficient to motivate and encourage them to use the diet diary. On the other hand, participants were concerned that deterioration in their overall health could negatively impact their use of the application over time. As one participant explained:

“Only if you had arthritis on your finger you know or if your eyes deteriorated. So I guess only a physical thing could prevent me from using it [the app].”

As for following the dietary recommendations, participants insisted that only internal controls such as their determination, awareness about their diet and knowledge about healthy eating would motivate them to alter their dietary behaviour and follow the recommendations. As one participant explained:

“I think I would just change my diet, if I thought I was eating [the] wrong diet. Like I said to you, before using this [the app] I assumed I was eating well for my age, until I realised the lack of fruit and veg in my diet.”

Another participant suggested that individuals' determination and commitment to a healthy lifestyle should be sufficient to encourage them to follow the recommendations; he also suggested that the use of the application in itself could also be a determining factor. As he explained:

“I think if you have committed yourself to using the app, you should commit yourself to following the recommendations. If you are not prepared to follow the recommendations, do not bother using the app, because it is going to be absolutely useless. So if you are committed to improving your health, you should at least believe what it says to you.”

Another participant highlighted frustrations about the lack of “clear” guidelines available to people about healthy eating. She explained:

“The government keeps changing recommendations. It would be good if there was a clear guideline [about] what’s good for you to eat. But as a general rule there’s a one line thing for healthy eating, so why does no one give clear instructions about what to eat?”

Overall, findings from this section suggest that internal factors such as motivation to eat healthily and awareness about their diet and health conditions play the most significant roles in affecting our participants’ use of the diet diary and adherence to the recommendations. Nevertheless, this is closely related to external factors such a lack of understanding and knowledge about required nutrition for AMD. The present findings seem to be consistent with other studies that suggest AMD patients have a definite lack of information and understanding of the link between AMD and nutrition, which is a cause for concern (Stevens *et al.*, 2014). The findings illustrate, however, how an appropriately designed assistive mobile technology can positively change this situation by educating uniformed users about healthy eating, in addition to motivating them (including users who are more aware about healthy eating) to eat healthily.

7.4 Study Limitations

While our evaluation studies have been successful in terms of contributing scientific knowledge concerning the impact of assistive technology on older adults with AMD as well as identifying indicative use patterns of such technologies and psychological factors that may predict technology use, they were not without their limitations (albeit some of which were unavoidable).

Firstly, evidence of our participants’ determination to use the diet diary and follow the recommendations, including participants’ desire to please the researcher, could be argued to

clearly illustrate occurrence of the Hawthorne (or observer) Effect. While some argue that this is an inevitable part of all usability studies (Raskin, 1994), we support assertions that there are significant differences between the context of the Hawthorne studies and the context of evaluation studies in the field of HCI (Macefield, 2007). Whilst, as previously discussed, we believe we did see some novelty (or even explicit Hawthorne) effect in our dietary consumption data for weeks 1-3, the impact seemed to dissipate over weeks 4-6 where we believe we did see more realistic usage data. Furthermore, participants were not under direct observation throughout the study: the researcher merely met with them at 7-10 day intervals (this was particularly important for extracting usage data from the devices' internal storage), thus lessening the impression of being 'observed'. We were *specifically* interested in our participants' *subjective* opinions and strongly encouraged participants to be as honest about and as 'natural' in their use of the app as possible in order to return to us meaningful data (i.e., it was stressed to participants that unjustifiably positive data was not necessarily as useful for us as more honest data). For example, when some of the participants occasionally mentioned that they would "*try harder*" for the researcher, they were assured that they should use the application as realistically as possible, and their lack of use was not seen as a failure or lack of commitment to the study. Further, our participants appreciated that this was an investigative study for which there was no right or wrong answer; they had no appreciation of how 'success' would be measured and so were not in a position to manipulate resulting data to impact that measure. Although there is clearly strong support for what we are trying to achieve, most of the participants recognised that the app was probably too late arriving to help them in their AMD health and any vested interest on their part was purely altruistic in terms of contributing to the betterment of the app for future generations – hence honest output was recognised as being of greatest value. Finally, we did not observe substantial differences between our Phase 5/6 and PD (who had known the researcher for much longer and were co-designers of the application) participants, suggesting that our findings are true reflections of respondents' attitudes and behaviours towards the app, regardless of level of involvement in its creation.

On a related note, it could be argued that the researcher's presence and the rapport she built up with the participants may have influenced the positivity of their responses to questions, feedback and determination to succeed. Based on our experience, however, we argue that such rapport and mutual understanding is *essential* for gaining the trust and commitment of members of otherwise reticent populations such that they can be empowered to be a strong driving force behind the success of IT design activities. We feel that achieving such user engagement would have been very challenging, if not impossible, without the establishment of the trusted working relationship between participants and the researcher and so would argue that it was a necessary and actually beneficial rather than limiting influence.

The mutual respect and strong bond that developed between the researcher and participants actually facilitated and encouraged open and honest exchange of ideas and opinions throughout. We have already illustrated a typical example of this when one of the PD participants was unable to continue with the longitudinal study due to her struggles to use the application with her magnifier; while feeling frustrated for not being able to take full advantage of the application, she felt at ease informing the researcher about this and taking the initiative to withdraw from Phase 6 of the study despite being a co-designer of the application. Furthermore, results revealed that our participants are not easily influenced by subjective norms or social pressure, suggesting that their determination to succeed was predominantly due to their perceived benefits and enjoyment derived from taking part in the study. Based on our experience, therefore, we posit that it is of crucial importance to build up such rapport with older adult participants in order to encourage them to participate in research studies, and, more importantly, not feel "*frightened*" to experiment with technology. Our participants' accounts (not derived from direct questioning but extracted from informal discussions as a result of thematic analysis) highlight the positive influence that taking part in appropriately designed research studies (and using assistive technologies) can have on their independence and quality of life.

Finally, some of the unavoidable sampling limitations (i.e., the self-selected convenience sampling, limited sample size, male and female ratio) identified in relation to our previous

research phases, are also pertinent for the evaluation studies. Care has, therefore, been taken to provide contextual information about the participants to assist with generalisation where possible. In addition, the level of detail provided by these examples may be transferrable across settings and populations (Yardley, 2000). For instance, it has highlighted the fact that older adults do adopt and use technologies, but only if the value and personal relevance is effectively communicated to them.

7.5 Summary

This chapter has presented the studies that were conducted as part of the final evaluation phases of this thesis research to evaluate the usability, acceptability and initial impact indicators of the prototype application. The findings of the two-phase human-subject evaluation activity indicate that perceived ease of use, perceived usefulness, internal control factors such as motivation to eat healthily, awareness about intake of food, health conditions and healthcare knowledge, play a considerable role in participants' acceptance and use of the diet diary application. The analysis of the study transcripts revealed four sub-themes pertaining to the perceived usefulness of the diet diary application as recognised by our participants: (1) the application raises awareness and facilitates self-monitoring of diet; (2) it encourages positive (diet) behaviour change; (3) it improves memory; and (4) it encourages learning. Additionally, other significant factors influencing and contributing to participants' experience of using technology included participants' determination and motivation, pride in taking part in the study, and showing interest in others.

We acknowledge that health behaviour such as healthy eating is only beneficial when maintained over a prolonged period of time (e.g., Conner and Norman, 2005), and thus to substantiate our claims of positive behaviour change further research (Chapter 9) is necessary, but we hope that findings thus far confirm that the use of the application has inspired positive behaviour change in the form of adherence to dietary recommendations. The following chapter evaluates and reflects on the *procedural* efficacy in terms of running such evaluations with our target user group.

Chapter 8. Reflection on the Evaluation Process

8.1 Introduction

As reported in Chapter 2, a methodological limitation of many reported studies to date is that they do not elucidate their research process clearly, failing to identify and discuss how user participation has been initiated and managed and thereby rendering their methods opaque and failing to provide support and guidance to the design community at large (Eghdam *et al.*, 2012).

As such, there are calls for future studies to clearly report on their design methods involving end users (e.g., Eghdam *et al.*, 2012; Vines *et al.*, 2014). Specifically, there is a methodological knowledge gap in the field of HCI concerning how best to ‘end’ participatory research. Attempts have recently been made to address this issue, but research has mainly focused on technology deployments ‘in the wild’ for large communities concerned with ensuring sustainability within the communities (e.g., Kapuire *et al.*, 2015; Taylor *et al.*, 2013). The research reported in this chapter attempts to at least start answering such calls for methodological documenting and reflection.

Firstly, cognisant of the potential negative effect that withdrawal of the participatory process may have on our users, we report on a focus group-based study, the aim of which was to address a methodological knowledge gap in the field of HCI concerning how best to ‘end’ participatory research. We then reflect on our application of guidelines for inclusive design (Leung and Lumsden, 2008) throughout our research study to support our mobile assistive technology design, development and evaluation process; based on our experience, we present an enhanced and extended version of the guidelines for working with older adults (with AMD).

8.2 Phase 7: Focus Group Study

Our studies thus far have revealed the importance of working together with our users via the adoption (and adaptation whenever necessary) of several UCD methods towards the goal of designing an acceptable mobile assistive technology. Further, these studies have also demonstrated the positive influence their involvement has had on participants. The unavoidable conclusion of the research project, however, means that the technology (the diet diary) will be withdrawn from participants (in its prototypic form it is not yet ready to be used without researcher support) and participants will no longer benefit as they have thus far from their affiliation with the researcher and their co-participants (with whom they have established friendships). Cognisant of the potential negative effect that ending involvement in the participatory process may have on individuals, we were determined to consider carefully how to best “end” the participatory process. Hence, we consulted the three participants we have worked with right from the onset of the project to solicit their opinions on how to bring closure to the process in as positive a way as possible. All participants were female; their ages ranged from 65-89 (mean age 75) (see Table 8.1 for participants’ characteristics).

Table 8-1: *Focus group study participants’ characteristics.*

| ID | Age | Gender | Experience with Computers | AMD Severity | Number of Years Since Diagnosed |
|----|-----|--------|---------------------------|---------------|---------------------------------|
| P1 | 89 | Female | Some | Dry one eye | 8 |
| P2 | 65 | Female | Moderate | Dry one eye | 2 |
| P3 | 72 | Female | None | Dry both eyes | 14 |

8.2.1 Study Protocol

One week after the Phase 6 evaluation meeting, the focus group session was conducted at one of the participant's homes (at the request of the group members who had become good friends). Participants' consent to participate was obtained as per previous research phases. To remove physical participation barriers associated with commuting to the venue, return taxi-based transport was arranged (and funded) for the two participants who had to travel to home of the third participant (the focus group venue). The focus group session lasted just under 3 hours: the session was audio-recorded, and a verbatim transcription of the recording was subsequently generated for analysis. After the session, participants were invited out for dinner to show appreciation for their invaluable involvement throughout the research agenda.

The aim of the session was to consider how to bring closure to the UCD/PD process in as positive a way as possible for participants who had been fully engaged with the project since its inception, and who we knew regarded the experience as an achievement that has changed their outlook on life. The session was structured to be evolving and reflexive, where participants' needs and suggestions underpinned how the session progressed. In the remainder of this chapter, we aim to provide insight into how to 'close' PD research (insight which is grounded entirely upon our participants' needs and suggestions), and offer an understanding of our participants' expectations on this matter rather than promote rigorous standards/methods for 'closing' participatory research.

8.2.2 Findings

As anticipated, all three participants were truly disappointed to have reached the 'end' of the project. Participants' main concerns included not being able to use the application to monitor their diet, not having regular contact with the researcher, and not being part of the "*participant-friendship*" circle they had formed. As an aside, it is important to note that participants who were involved only in the evaluation phase had also expressed similar concerns in terms of handing back the application and having no contact with the researcher after the study.

All three of our focus group participants felt it was imperative that researchers remain in contact with participants after active research ceases. In the same way, they were grateful for the opportunity to be asked to share their views and opinions on the methodological aspects of the project. Encouragingly, our participants thought our project was exemplifying of how human-subject studies *should* be conducted in general. Participants argued that it is of crucial importance for researchers to feedback information to participants about the outcomes and future directions of a project. Specifically, participants suggested the following four questions should be addressed:

“Was the project successful?” Participants wanted to be informed about how successful the project was deemed to be by the researchers in order to understand the value of their contributions. In our case, this primarily involved sharing other participants’ views and feedback on the design of the diet diary application over which they had stakeholder ownership. Furthermore, it also involved a discussion on how findings from the final phase of the project met the overall aims and objectives of the project from the researcher’s perspective. Our participants had been informed right from the onset of the project that this formed part of the researcher’s PhD research, and thus were cognisant that the diet diary application was a prototype and not a finished product and that their final suggestions for improvements (as elicited from the evaluation study) could be acted upon only after the completion of this project when sufficient funding is secured for deployment of the application. Thus *“success”*, in our case, did not imply a finished product but more qualitative findings in terms of the impact that the application has had on the lives of the participants who were involved in the study. This was all discussed with the participants whose expectations we seem to have managed successfully via our continued, open and comprehensive dialogue with them throughout the study and as a consequence of the trusted relationship that had also been established between all parties.

“Was participants’ contributions helpful?” Closely associated with the aforementioned question, our participants argued it was also important to be informed if their contributions

were helpful. They reasoned that such understanding would enhance their self-assurance and self-confidence. Furthermore, they maintained that learning how they “*got on with the project*” could encourage and motivate them to take part in other similar studies. In fact, one participant informed us that she had signed up for another study with the Vision Sciences School at Aston University. As she explained:

“Well, I have already signed up to another study with a professor for AMD, so I am really excited to get involved in similar projects. Let’s hope they will find me as helpful as you did.”

Throughout the course of the project, our participants were persistently reminded about the importance of their contributions and the fact that we were learning from them, as they are best equipped to inform (and direct) our research based on their knowledge of their own technological needs, abilities and expectations. In fact, the final focus group meeting was a concrete example of the value of their contributions, in that we were learning from them how to bring closure to our project.

“In what ways did their involvement benefit the project?” Our participants sought to know how and in what ways their involvement benefited the project – what were the advantages gained from such collaboration (in terms of the researcher’s and other participants’ perspectives)? As one participant explained:

“Especially for someone who does understand AMD and its worst point, it would be wonderful to think that all my time I have spent with it, it has been useful, it has come back as favour for other people like me, or researchers like you.”

Throughout the course of the project, our participants were always informed what we had learned from their involvement in each phase of the project. For the evaluation phases, participants were informed how examining their use of the application could help us understand how similar (mobile) assistive technologies could be designed in future to be deemed acceptable and usable by older adults (with AMD).

“Where is the project at and what is happening?” In this instance, participants were more concerned about the sustainability of the project, and what progress the project was making throughout and will make after their involvement. For example, there was a lengthy interval

(due to development of the application) between the PD activities (Chapter 4) and the evaluation phases where participants finally had the opportunity to use the prototype they co-designed. During this period, however, the researcher was in regular contact (via phone) with all co-designer participants, updating them on the progress of the project. Encouragingly, one of the participants used that as an illustration of best practice for “*keeping in touch*” with participants. She recalled:

“Remember, like you used to do after the design sessions, when you were working on this [the app], you would call us and say: ‘I am still programming’; and that was really reassuring that you hadn’t forgotten us and kept us in the loop.”

At the time of writing, we have maintained the same practice and have been in regular contact with all of our PD and some (those who expressed associated interest during their end-point interview) of our evaluation study participants. We also intend informing our participants about the successful submission of this thesis and when/if further funding is secured to continue with the project (future research directions are discussed in Chapter 9).

With regards to the medium and frequency of the communication/notification about project updates, after much deliberation participants suggested circulating a yearly “*news bulletin*” with all the updates and future directions of the project. Additionally, participants suggested that the research should send occasional text messages or, more preferably, telephone participants to “*chat*”. Our participants were, however, sympathetic and considerate about the time and effort required from the researcher for such an undertaking, and agreed that the most appropriate medium of communication would largely depend on the number of participants to be contacted. Participants suggested that, with small numbers of participants (as in our case), a “*face-to-face*” meeting would be much more desirable (frequency depending on the project’s development). As one participant explained:

“I mean 10 is manageable ... we could also meet physically, whereas if it is 100, then you would be stuck. I think with 10 we would really benefit from meeting with you face-to-face. The occasional text/phone call would be great, but gathering or meeting is what we need – the text and all that is a bit inhumane, and it doesn’t stimulate your interest because already your thinking ‘oh Lilit is going to be doing this and that, which sounds really interesting’.”

Additionally, participants suggested organising annual meetings for all participants to inform them about any updates and news, but also to allow for socialising. As one participant explained:

“When you get to our age, with our problems, your social life becomes very, very limited... and it would be not only to know about the project but to also socialise.”

Encouraged by our participants’ keen interest (and request) to stay in touch and be informed about the future directions of the project, and in an attempt to establish a centre for engagement/collaboration between researcher(s) in (mobile) assistive technology and potential end users, we proposed to ‘register’ our participants on a participants’ panel, whereby they could not only be contacted as discussed above, but they could also consent to be invited to collaborate in future, similar projects. Promisingly, all our participants (including ones from the evaluation study) welcomed the idea and agreed to be sign up to such a panel. More importantly, participants suggested acting as a contact point or “pioneers” for other (newly recruited) participants to advise and direct them from a participant’s perspective; they hoped this would encourage other older adults (with AMD) to be more receptive and “open” to technology, and inspire them to “take full advantage” of the benefits gained from participating in similar research studies. As one participant explained:

“I think you could get us to come and talk to them. Because we all have different perspectives we could actually dispel their fears. You could get a group that weren’t sure, and we could talk to them and say look, it doesn’t matter if you can’t use [a] computer; it doesn’t matter what you know, because the study will, I don’t mean nurse you through it, that’s probably the wrong word, but you will get support all the way and you will learn something that you have never expected to learn, so the only way to do this is to talk to other people.”

8.2.3 Summary Discussion

In some studies where technologies are deployed and, potentially, initiatives are sustained, participants can continue to use (and benefit from) technology after active research ceases. In our case, however, handover of technology was not a prudent option as our research prototype is not sufficiently robust to make unsupported use feasible or sensible; leaving behind these prototypes (with participants) would place the burden on participants to maintain them without support. Although an option in some studies would be to leave

participants with the physical device as well as the app (where users didn't already own a smartphone or tablet), this was not also not feasible in our case given resource availability; additionally, none of our participants even suggested keeping their devices. As already mentioned, our management of participants' expectations seems to have been effective in this regard given that they seemed to fully appreciate the boundaries of the research responsibilities (e.g., that the technology would not be supported long-term by the project itself).

Our participants raised important questions that need to be addressed upon completion of a project such as ours in order to facilitate participants' self-reflection and evaluation of their involvement. They felt it was imperative that researchers remain in contact after active research ceases and believe that participants will always be keen to understand how their involvement benefitted a project and how successful the project has been in general. While the former issue is more implicit and *should* be communicated to participants throughout the study as well as at its conclusion, the latter issue is not as easily defined and interpreted and therefore communicated: what constitutes 'success' is in itself an emerging research area within HCI that requires investigation in terms of how to define and thereafter evaluate it (Taylor *et al.*, 2013).

An important realisation to emerge from our findings and associated reflection is that appropriate steps must to be taken right at the beginning of a participatory research agenda (and maintained throughout) to ensure that participants are well informed about the directions the project is taking and how their involvement and contributions fit within the research agenda. These issues should not be considered or discussed only at the end of the project but expectations should be managed throughout the duration of the project: researchers have a responsibility to ensure participants' needs are supported throughout and expectations met at the end of the project.

Based on our experience, we suggest researchers maintain contact with participants after the end of the project to inform them about updates and future directions of the research. Participants who enjoyed taking part in one project are likely to want to continue to participate in similar studies; moreover, as our participants suggested, they would be keen to act as a contact point for others in their community and encourage them to become more involved in research studies. It is, therefore, important for a researcher to gain the trust and commitment of members of an otherwise reticent population such that they are then willing to encourage other members of their community to get involved. Such encouragement could be significant to the success of future studies given the known difficulty of recruiting participants with special needs in niche domains to studies of this type. Nevertheless, there is clearly a limit (in terms of time, resources and willingness) to the extent to which researchers and participants can maintain such engagement after the conclusion of a programme of research: as such, expectations in this regard need to be as carefully managed as those during the rest of the study. In our case, as already noted, we are maintaining regular contact with our PD and two of the evaluation study participants; all our participants are also registered on our participants' panel and keen to be invited to collaborate on future similar projects.

8.3 Reflections on Our Application of Guidelines for Inclusive Design of Assistive Technologies

By following the guidelines (introduced in Chapter 2) as proposed by Leung and Lumsden (2008) in undertaking research reported in this thesis, we feel we have been successful in minimising challenges associated with enabling niche target users such as older adults with AMD to effectively participate in the design, development and evaluation of technology. This section illustrates and reflects on the practical application of those guidelines to support our engagement and collaboration with older adults with AMD. Based on our practical experience, those guidelines are then extended and enhanced for the benefit of future researchers.

Guideline 1: Work with Existing Support Organisations

On reflection, our engagement with support organisations (see Chapter 3) was critical to the success of our design and evaluation activities. Access to and recruitment of participants for our studies would not have been possible without this level of targeted engagement. Our involvement with the support organisations – such as the Macular Society – identified that individuals' reluctance to participate in research studies is often the consequence of a misconception that laboratory-based research essentially uses people as experimental subjects rather than experts living with their disability. It is therefore important that researchers recognise the potential for and fully appreciate the essence of such attitudinal road-blocks such that they are able to address any such misconceptions about involvement in a given study; in our case, we had to work hard to, but were ultimately able to convince, our participants via discussion and action, that we considered them as 'experts' in living with their disability and that our research was entirely aimed at meeting their needs (rather than the other way around).

Guideline 2: Assess Target Users' and Domain Experts' Needs, Abilities, and Expectations

Our experience reinforced in our minds the importance of placing the anticipated end users of assistive technology in a central, inclusive role in the design of the technology. If one does not suffer from a disability, it is very hard to anticipate the complexities (and perhaps, to an even greater extent, the knock-on complications) associated with living with the condition and we are certain that we would not have been able to relate to the problems, preferences, and coping strategies of our target users had we not had such close involvement of members of our user group.

We deliberately segregated the involvement of individuals with AMD and domain experts to allow for different types of discussion to occur and to leave the balance of 'power' in the hands of the individuals with AMD (i.e., to avoid "*white coat syndrome*" if a clinician was to be present in a combined focus group). As discussed in Chapter 3, it is interesting to note that

the experts in our case were largely negative about the prospect of the application, in stark contrast to the positivity with which the concept was being received by the individuals with AMD themselves. Whereas the individuals with AMD had several sessions of engagement with us and each other to digest the concept and fully and collaboratively explore its implications and perceived usefulness to arrive at a positive outlook on the project goals, the experts merely met with us for a short one-on-one interview, thus didn't have the benefit of seeing the positivity of target users' reaction to the prospect of mobile assistive technology before dismissing it as infeasible for this user group. Furthermore, whilst the clinicians were dismissive of the participants in our design groups as being too far advanced in their AMD to benefit from the intended application, the participants themselves adopted a far more altruistic viewpoint, acknowledging the target application would likely be of no direct benefit to them but recognising its potential for positive impact on generations to come and appreciating that we were considering them as the 'experts' in living with the condition who could therefore speak from a position of authority in terms of directing our design efforts for the benefits of future individuals with AMD.

It is only through the direct involvement of our target users and domain experts that we were able to effectively assess their needs and expectations. Our observations of differences in reaction to our research goals highlight the challenges associated with engaging the domain experts in the research process, and the potential need to take appropriate measures to ensure that they don't unduly influence the process with ill-placed assessment of target end users' attitudes and willingness to push their own boundaries. In our case, the domain experts appeared far less open to mutual learning than the individuals with AMD, remaining largely set in their pre-conceived opinions of the feasibility of technological solutions for individuals with AMD and less able/willing to envisage beneficial innovation than the individuals themselves. This difference in opinion is interesting and we feel would have been problematic had we not engaged with the two groups of stakeholders separately. It shows that even the experts can underestimate the resolve of the individuals with disabilities who, if appropriately engaged in the process, can show amazing enthusiasm and disposition to be

early adopters of technology specially designed for them. It also highlights potential gulfs in motivation between the target end users (individuals with disabilities) and the domain experts. In this instance, with the benefit of hindsight, we are confident that we took the right approach to engaging our stakeholders, this approach having been somewhat directed by initial interaction with experts which suggested to us that their integration into the focus groups and other activities would not have been a positive move. Highlighting the fact that it isn't necessarily engagement of the individuals with disabilities that is most problematic, our experience indicates that we need to reflect further on better ways to engage the experts in projects like this.

Guideline 3: Choose a Design/Evaluation Technique and Analyse its Requirements

The choice of the PICTIVE PD approach (see Chapter 4) seemed a natural fit with the identified capabilities of our target end users and the objectives of the design activities. Furthermore, the method lends itself very well to adaptation relative to the specific needs of individual participants as discussed in Chapter 5. The method is also ideally suited to working with small groups – a bonus when working with special needs populations where identification and recruitment can be problematic.

Guideline 4: Adapt the Chosen Approach to be Sympathetic to the Target Users' Abilities

Chapter 5 reports on the extent of adaptation required for our AMD participants given their specific disability and comorbidities. Nevertheless, the method was well suited to our context and adaptations were successful.

Guideline 5: Clearly Communicate the Nature of Participants' Involvement

Although care needed to be taken to ensure communication was clear and comprehensive, it merely required appreciation of appropriate communication media (based on early assessment of participants' needs and capabilities) and the allocation of a longer period of

time to achieve clear understanding on both parts and to seek informed consent. Interestingly, due to their more significant involvement in our process, we expended a lot more effort communicating our goals to our AMD participants than AMD domain experts; with hindsight, this might account for the very different attitudinal approaches to our work between the two groups. This highlights the need, in some contexts, to perhaps spend as much time assessing the clinical experts' needs, opinions, expectations, and communication requirements (as per Guideline 2) as assessing those of the individuals with disabilities; the natural, but perhaps flawed assumption, is that the former will require less effort than the latter, but this is clearly not always true. Furthermore, it suggests that it may be beneficial for the experts to be able to observe target users' reactions to the project before themselves being actively engaged as this might encourage them to be more open minded if applicable.

Guideline 6: Attempt and Refine the Approach

Throughout our research, our flexibility of and sensitivity to methodological adaptation allowed us to fully engage our participants in a meaningful and well-supported way in the participatory design of technology to support their disabilities. Whilst relatively minor adaptations, they proved significant in terms of the participants' overall satisfaction with the process and their subsequent contributions to and confidence in their ultimate designs.

Guideline 7: Evaluate the Technology in Different Contexts

We opted for a field-based evaluation of the study such that the usability of the app would be evaluated in natural use-case settings. Furthermore, throughout our research (and particular our evaluation phases), we have been careful to not only evaluate the technology itself, but also to carefully reflect on the methods we have been adopting and adapting to achieve our research goals. We have identified emergent themes of participant mutual learning, socialisation, and empowerment as powerful bi-products of the inclusion of individuals with disabilities in research studies adopting UCD methods.

8.3.1 Extensions and Enhancements to the Existing Guidelines

Based on our experience, we restate the original guidelines (Leung and Lumsden (2008) in order to enhance/elaborate on (Guidelines 1-7) and extend them (Guideline 8) to focus specifically on working with older adults (with impairments).

Guideline 1: Work with Existing Support Organisations

- *Consider attending local older adults' support group meetings/gatherings:* attend and take part in older adults' group activities in a similar way that they are encouraged to participate in research studies in order to gain their respect and trust. Becoming involved in organisations' activities provides an opportunity to get to know the people you are recruiting. This, in turn, can help to raise older adults' awareness about research opportunities, and alleviate possible reservations and/or misconceptions about research studies.

Guideline 2: Assess Target Users' and Domain Experts' Needs, Abilities, and Expectations

- *Everything about older adults' experience matters:* take time to understand older adults' needs and be sensitive to their age-related impairments (e.g., sensory, motor, cognitive) that may impact the study design and process. Older adults are investing time and effort into a research project, and are more likely to withdraw if their experience is not a positive one, or if the study is not well designed to accommodate their specific needs and abilities.

Guideline 3: Choose a Design/Evaluation Technique and Analyse its Requirements

- *Remain sympathetic and responsive to the needs of older adults' throughout the course of the study:* ensure the chosen technique/method creates a sense of team work, where all its members' views and opinions matter and, more importantly, it motivates your participants.

Guideline 4: Adapt the Chosen Approach to be Sympathetic to the Target Users' Abilities

Generalisations of the adaptations or methodological concessions we accommodated for our PD activities with older adults are documented in Chapter 5 and are briefly reiterated for completeness below:

- *adapt your selected method/approach for the specific older adult user group requirements;*
- *accommodate comorbidity issues;*
- *use metaphors and pertinent tangible objects to encourage and support envisioning of technology;*
- *use non-technical (accessible) language and provide ample explanations to avoid mismatched expectations; and*
- *establish a friendly atmosphere.*

Guideline 5: Clearly Communicate the Nature of Participants' Involvement

- *Learn to communicate in language meaningful to older adults:* older adults appreciate and take pride in participating in research studies if they understand the project and their involvement, and are treated equally and with respect. Carefully consider how to explain the study design and process, their role and what is expected of them, and why their involvement and contributions matter in language which resonates with them.

Guideline 6: Attempt and Refine the Approach

- *Preserve procedural flexibility during the course of the study:* although older adults delight in taking part in research studies they prefer to do it in their own way and at their own pace. Advise participants about necessary procedural refinements and provide updates on their (and the project's) progress throughout.

Guideline 7: Evaluate the Technology in Different Contexts

- *Involve older adult participants in the decision making:* ensure older adults' needs and abilities are taken into account when designing studies. Controlled, lab-based settings may not always be suitable for older adults due to their impairments, particularly when they have to travel to the site for the study, and may find the controlled environment uncomfortable. For more "*real-world*" evaluations, some participants may require researchers to come to their homes; others may be less inclined to invite researchers into their homes and would prefer to travel to the study site so remain flexible to the older adults' preferences as far as possible.

Guideline 8: Advise Users and Domain Experts on How the Study Will 'End'

It is important that older adult participants (and domain experts) are advised on how the participatory research will be 'ended' in order to minimise the potential negative effect that withdrawal of the participatory process may have on participants. Our participants suggested that the following questions should also be discussed at the end of participatory research:

- "Was the project successful?";
- "Were the participants' contributions helpful?";
- "In what ways did their involvement benefit the project?"; and
- "Where is the project at and what is happening?"

8.4 Working with Older Adults: Researcher's Reflection

It is evident that the successful researcher's rapport with all participants of the study has shaped the outcomes of this research agenda. From our participants' perspective, they seemed to see the researcher as a potential source of information in terms of technology use, healthy eating and lifestyle, future research on AMD, causes, treatments and preventative methods for AMD. Furthermore, given the age differences between the researcher and participants (the researcher is a *lot* younger than the participants), the participants almost seemed to adopt a grandparent-grandchild type affiliation with the

researcher. During discussions, participants were interested to learn more about the researcher and her future goals and ambitions and were similarly keen to stay in touch after the completion of the researcher's PhD research, as well as to collaborate on future projects, such as their affection for and trust in the researcher.

From our perspective, we found it enlightening to work with older adults with AMD – to work collectively to achieve a common goal with different generations, with different life experiences which largely represented a lack of IT experience, and different levels of impairment was thoroughly rewarding. While rewarding, however, the experience was not without its challenges. Above all, it was emotional for the researcher to empathise with participants' difficulties in terms of living with their impairment and to listen to their life stories, both happy and sad. Tangential discussion with participants on these issues often arose during interviews, focus groups, the PD and evaluation sessions, and it was sometimes difficult to find subtle ways to divert conversation back to the task at hand in order to retain a work focus.

Secondly, due to the age differences between the researcher and participants, the researcher occasionally found it awkward trying to 'teach' participants who had a great wealth of life experiences and knowledge in other domains. She also found it challenging at times to try and place herself in the shoes of the participants in terms of technological knowledge, in order to start building their understanding from bare 'roots' – reflecting an observation of one of the participants:

"But sometimes when a child or adult doesn't understand something, it is even better for you because then you have to take your mind back to where they are, so you have to peel back, which is what I like. It's like peeling an onion where you go to the roots and start building from there".

Nevertheless, participants' willingness to learn and support themselves was a key motivational factor for the researcher. Further, participants' reassurance to the researcher that the proposed solution was going to be beneficial to them (and others to which it could be generalised) was an incentive and great source of motivation and perseverance for the

researcher; it was, in fact, of fundamental importance in overcoming challenges along the way.

8.5 Summary

In this chapter, we have reported on findings from our final research activities (Phase 7) which aimed to address a methodological knowledge gap in the field of HCI concerning how best to ‘end’ participatory research. Findings from this study advocate the importance of (a) advising participants directly as to how closure will be brought to their participation, and (b) being willing to maintain contact with participants after active research ceases.

Furthermore, we have reflected on our practical application of guidelines for inclusive design (Leung and Lumsden, 2008) in order to illustrate how, with careful thought and adaptability to the needs, abilities, and expectations of older adults, it is possible to successfully integrate older adults (with AMD) into the design and evaluation process for innovative assistive technologies. On the basis of this reflection, we have enhanced/elaborated on and extended the original guidelines to focus specifically on working with older adults (with impairments) in order to help future researchers to overcome the challenges inherent in involving older adults (and domain experts) in the design and evaluation process for such technology.

In so doing, we hope we have (a) illustrated how it is possible to minimise challenges associated with enabling target older adults to effectively participate in the design and development of technology, and (b) highlighted the benefits of following a participatory user-centred approach with older adults. Furthermore, we hope that our reflections on the practical application of the guidelines for working with older adults (with impairments) will be useful to others engaging in design and development in this very rewarding field. Finally, since inclusive methods to accommodate users with special needs (disabilities) are also applicable and result in good practice for users without special needs, we are confident that our reflections on the guidelines will have further reaching benefit as well.

Chapter 9. Conclusions and Further Research

9.1 Thesis Conclusions

This dissertation has described UCD research that was conducted to design, develop and evaluate an assistive diet diary application for older adults with AMD. The research considered – taking people with AMD as a case study – how best to work with older adults to achieve sympathetic design of assistive technologies based on their needs, views and capabilities. Recognising the importance of good nutrition and the challenges involved in designing for people with AMD, this dissertation has presented seven phases of research that were conducted to: (1) establish contact with local community support groups for people with AMD in order to ‘start’ the UCD process; (2) understand their experience with and attitudes towards technology; (3) attain a true sense of ‘*being there*’ with representative participants in their homes; (4) employ participatory design techniques to inclusively create paper prototype designs of our proposed technology; (5) develop a prototype diet diary application; (6) evaluate the usability and accessibility of the prototype application and the applicability of our research approach; and (7) consider how best to ‘*end*’ participatory research agendas (see Figure 9.1 for an overview of the phases of this research).

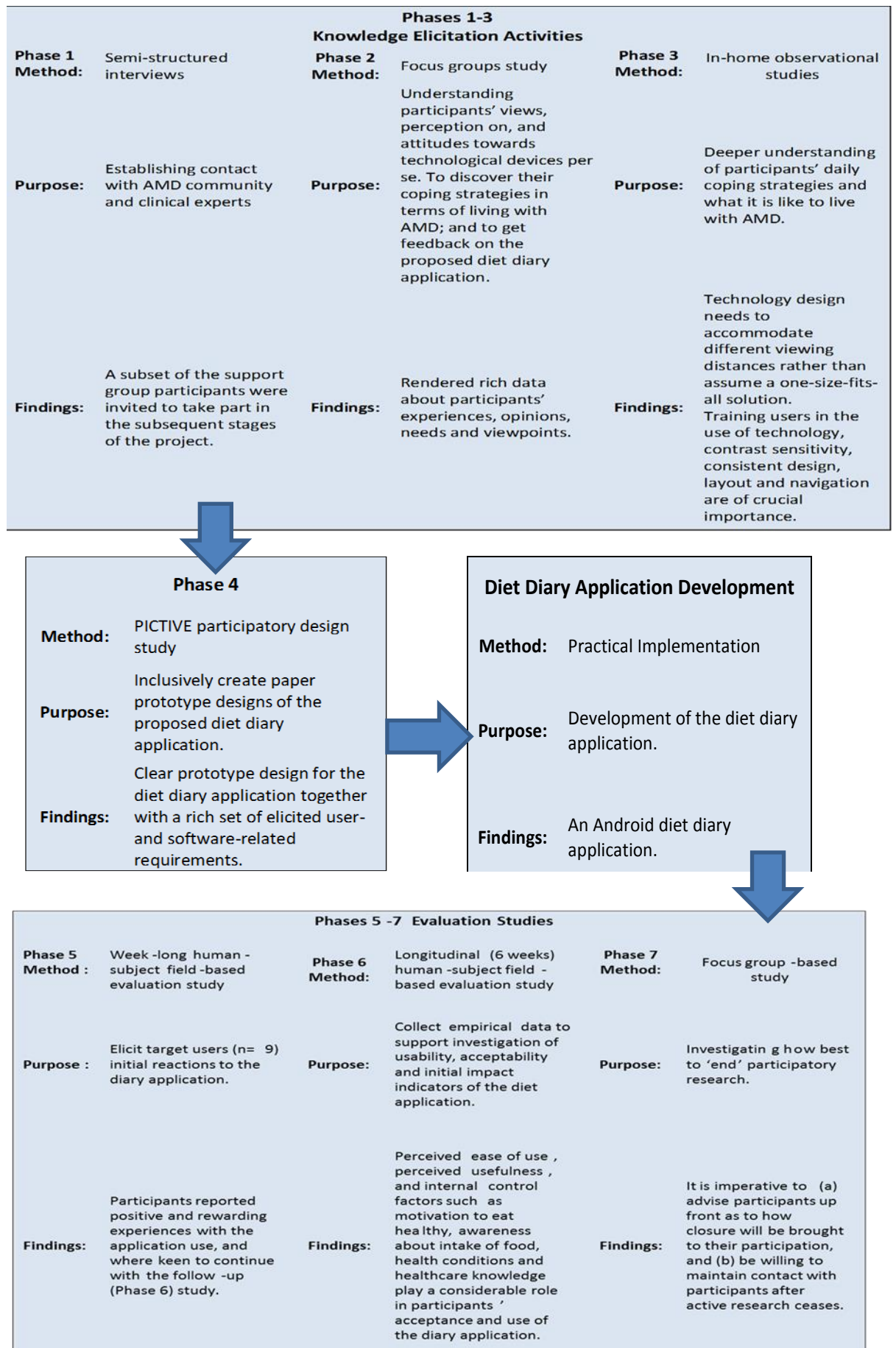


Figure 9-1: Phases of the research presented in this thesis.

Phase 1 of the research involved establishing contact with the AMD community to start getting to know the community and to recruit participants. Following this, focus groups (Phase 2) and in-home observational studies (Phase 3) were adopted to collect qualitative ethnographic data about the needs and views of older adults with AMD. Results from these exploratory fieldwork activities (Phases 1-3) illustrated that current technological devices are not generally designed with older adults with special needs in mind, but also endorsed the fact that technology can have a positive impact on this user group if designed based on their needs and wants. These phases of research demonstrated the extent to which existing support groups for people with AMD represent an ideal vehicle for establishing contact with the community and recruiting participants for studies provided the process is handled sympathetically and the research team invest the necessary effort in 'getting to know' the community before commencing research activities. These research phases illustrated that individuals' reluctance to participate in research studies is often the consequence of a misconception that laboratory-based research essentially 'uses' people as experimental subjects rather than as experts living with their disability, highlighting the importance for researchers to recognise the potential for, and fully appreciate the essence of, such attitudinal road-blocks such that they are able to address any such misconceptions about involvement in a given study.

These findings then formed the basis of the Phase 4 study, which adopted the PICTIVE PD approach to inclusively create paper prototype designs of the proposed application for and with users with AMD to support their dietary-based AMD progression retardation over time. The results of this study, in tangible form, were a clear prototype design for the proposed diet diary application together with a rich set of elicited user- and software-related requirements which represented the needs and preferences of older adults with AMD. A subsequent chapter reflected on the experience of adopting and adapting the PICTIVE participatory design approach to support effective design with and for special needs user groups such as older adults with AMD, discussed dominant design themes – *Mutual Learning, Empowerment and Socialising* – emerging from the PD activities, and suggested recommendations for (or

further insight into) how direct involvement of special needs users might be successfully achieved with relatively easy adaptation and/or accommodation of standard design practices.

Following the adoption of mixed method approaches to uncover the needs and preferences of older adults with AMD, an Android prototype diet diary application has been developed in an attempt to promote independent living and enhanced wellbeing for older adults with AMD. A novel UI (based on our participants' paper prototypes) for the application has been developed in an attempt to maximise the usability and accessibility of the application for this user group. The application has been developed to allow end users to conveniently record dietary information and to, in response, automatically provide them with customised dietary advice, drawing on evidence-based recommendations and captured data to empower older adults with AMD to make informed dietary choices.

To collect empirical data to support investigation of the usability, acceptability and initial impact indicators of the prototype application, a two-phase human-subject field-based evaluation study was conducted (Phases 5 & 6). Findings from this study revealed that perceived ease of use, perceived usefulness, and internal control factors such as motivation to eat healthily, awareness about intake of food, health conditions and healthcare knowledge play a considerable role in participants' acceptance and use of the diet diary application. The analysis of the study transcripts revealed four sub-themes pertaining to the perceived usefulness of the diet diary application: the application raises awareness and facilitates self-monitoring of diet; it encourages positive (diet) behaviour change; it improves memory; and it encourages learning. Additionally, other significant factors influencing and contributing to participants' experience of using technology included participants' determination and motivation, pride in taking part in the study, and showing interest in others.

The final Phase 7 study was conducted to address a methodological knowledge gap in the field of HCI concerning how best to 'end' participatory research. Findings from this study advocated the importance of (a) advising participants up front as to how closure will be

brought to their participation, and (b) a willingness to maintain contact with participants after active research ceases.

9.2 Contribution to Scientific Knowledge

Section 1.2 outlined four research questions that underpinned and focused the research documented in this dissertation. This section reflects on these research questions in terms of the scientific output of this research agenda.

1. What constitutes effective practice in terms of engaging older adults with AMD (and more generally) in user-centred, participatory research for assistive technology design and development?

Our knowledge elicitation activities (Chapter 3), PD (Chapter 4) activities, and evaluation studies (Chapter 7) investigated, in an applied way, the answers to this question. Reflections on our practice indicated the importance of carefully initiating, planning and managing older adults' engagement throughout the course of the research. Specifically, based on our PD activities (Chapter 5) with older adults, we suggested recommendations for (or further insight into) how direct involvement of special needs users might be successfully achieved with relatively easy adaptation and/or accommodation of standard design practices. These recommendations were to:

- *adapt selected methods/approaches to match the specific older adult user group requirements;*
- *accommodate comorbidity issues;*
- *use metaphors and pertinent tangible objects to encourage and support envisioning of technology;*
- *use non-technical (accessible) language and provide ample explanations to avoid mismatched expectations; and*
- *establish a friendly atmosphere.*

Furthermore, reflecting on our practice, we enhanced and extended general guidelines for inclusive design of assistive technology with special needs users (Leung and Lumsden, 2008) to focus specifically on working with older adults (with impairments):

- *Consider attending local older adults' support group meetings/gatherings:* attend and take part in older adults' group activities in a similar way that they are encouraged to participate in research studies in order to gain their respect and trust. Becoming involved in organisations' activities provides an opportunity to get to know the people you are recruiting. This, in turn, can help to raise older adults' awareness about research opportunities, and alleviate possible reservations and/or misconceptions about research studies.
- *Everything about older adults' experience matters:* take time to understand older adults' needs and be sensitive to their age-related impairments (e.g., sensory, motor, cognitive) that may impact the study design and process. Older adults are investing time and effort into a research project, and are more likely to withdraw if their experience is not a positive one, or if the study is not well designed to accommodate their specific needs and abilities.
- *Remain sympathetic and responsive to the needs of older adults' throughout the course of the study:* ensure the chosen technique/method creates a sense of team work, where all its members' views and opinions matter and, more importantly, it motivates your participants.
- *Learn to communicate in language meaningful to older adults:* older adults appreciate and take pride in participating in research studies if they understand the project and their involvement, and are treated equally and with respect. Carefully consider how to explain the study design and process, their role and what is expected of them, and why their involvement and contributions matter in language which resonates with them.

- *Preserve procedural flexibility during the course of the study:* although older adults delight in taking part in research studies they prefer to do it in their own way and at their own pace. Advise participants about necessary procedural refinements and provide updates on their (and the project's) progress throughout.
- *Involve older adult participants in the decision making:* ensure older adults' needs and abilities are taken into account when designing studies. Controlled, lab-based settings may not always be suitable for older adults due to their impairments, particularly when they have to travel to the site for the study, and may find the controlled environment uncomfortable. For more “*real-world*” evaluations, some participants may require researchers to come to their homes; others may be less inclined to invite researchers into their homes and would prefer to travel to the study site so remain flexible to the older adults' preferences as far as possible.
- *Advise users and domain experts on how the study will ‘end’:* it is important that older adult participants (and domain experts) are advised on how the participatory research will be ‘ended’ in order to minimise the potential negative effect that withdrawal of the participatory process may have on participants.

2. What do older adults with AMD need and expect in terms of an assistive mobile technology to manage their dietary health associated with AMD disease progression and what indicators are there that an application designed to meet such needs and expectations affects dietary behaviour change?

Our design (Chapter 4) and evaluation (Chapter 7) of the diet diary application provided answers to this research question. A user-led prototype design for a usable and accessible mobile application for older adults with AMD was derived from our participatory design activities involving direct design input from older adults with AMD. A major challenge identified in terms of the user interface design was the placement of UI components such

that the resulting technology could be used effectively and independently by persons with AMD. This required the atypical placement of the UI components around the edges of the UI, leaving the centre clear. We also identified numerous issues associated with current technology (especially UI) design in terms of its suitability for older adults, highlighting that rendering technology usable to older adults is not merely a case of enlarging what is on screen, but that a deeper appreciation of older adults' mental models, opinions, and preconceptions is required in order to design bespoke applications that truly consider their needs. Our evaluation studies (reported in Chapter 7) indicated that our participatory design activities had been effective in terms of delivering a UI design that was considered usable by its intended user group. Our findings indicated that perceived ease of use, perceived usefulness, and internal control factors such as motivation to eat healthily, awareness about intake of food, health conditions and healthcare knowledge, play a considerable role in participants' acceptance and use of the diet diary application. Overall, a combination of participants' self-reported adherence to dietary recommendations and dietary change and recorded evidence from auto-logged use of the application illustrated that indicators of positive dietary behaviour change were observed across the participant group.

3. How should the acceptability and impact of a diet diary for persons with AMD be evaluated in order to identify use patterns and psychological factors that predict behaviour change in response to the dietary recommendations?

Our evaluation study reported in Chapter 7 was designed to address this question. The two-phase human-subject evaluation study was conducted to evaluate the usability, acceptability and initial impact indicators of the prototype application. Usability, acceptability and impact of the application were assessed using a) objective measures of the application use, and b) self-reported satisfaction with the application. These measures were combined with insight obtained from auto-logged data to evaluate the effect of providing dietary recommendations: findings revealed that the application raised awareness and facilitated self-monitoring of diet; it encouraged positive (diet) behaviour change (in terms of adherence to dietary recommendations); improved memory; and encouraged learning.

4. What constitutes best practice in terms of bringing closure to participatory research in as positive a way as possible for older adults?

To answer this question we conducted a focus group-based study (see Chapter 8) to explore the issue with older adults with AMD who had been part of our lengthy participatory design process. Results from the study advocated the importance of advising older adult participants (and domain experts) as how the participatory research will ‘end’ in order to minimise the potential negative effect that withdrawal of the participatory process may have on participants. It emerged that the following questions should also be discussed at the end of participatory research:

- “Was the project successful?”;
- “Were the participants’ contributions helpful?”;
- “In what ways did their involvement benefit the project?”; and
- “Where is the project at and what is happening?”.

The aforementioned findings also formed part of extended guidelines (see Chapter 8) for working with older adults (with impairments).

9.2.1 Future Research Directions

The conduct of this research not only led to the tangible contribution to scientific knowledge outlined throughout the dissertation and summarised above, but it also led to the identification of future research directions – a contribution to scientific knowledge in its own right.

The diet diary app is very prototypic in its current form, and so an obvious avenue for future research is to continue development of the diet diary app itself. Refinement of the application should be based on analysis and feedback reported in Chapter 7 in order to improve its ease of use and to further improve its dietary recommendations. Our vision would then be that the application be publicised and distributed free of charge to older adults with AMD, ideally via support networks with whom we worked to achieve our research outputs.

Although the current diet diary prototype does monitor user interaction (e.g., button presses) in order to facilitate UI adaptation based on observed changes in user interaction patterns over time (e.g., as a result of degenerating visual acuity), the algorithm needs to be enhanced to best support *automatic* UI adaptation over time based on degenerating capabilities which is of utmost importance to people with degenerative disabilities such as AMD. Hence, we suggest that the following research question be explored:

- *How can we best leverage intelligent computing to develop an adaptation method/algorithm whereby the user interfaces to mobile assistive technologies are automatically adapted based on observed use by people with degenerative disabilities?*

Given that older adults with AMD see relatively slow progression of their visual acuity, future research would be required to design an evaluation study that could assess the effectiveness and acceptability (as well as potential impact on usability) of the automatic UI adaptation algorithm. Hence, a novel evaluation process is required to explore the following research question:

- *How effective is the automated UI adaptability and personalisation (based on visual acuity) in terms of usability and acceptance?*

Within the scope of the current research, a 6 week usability-focused evaluation of the system was conducted with a limited number of users. We would propose to expand our evaluation efforts to include much longer longitudinal field evaluations, wherein several users would use the device for an extended period of use in order to fully assess the acceptability to and impact of the system on persons with AMD. Such a study would lead to deeper appreciation of issues such as: 1) the extent to which the diary encourages *sustained* positive behaviour change over time; 2) the extent to which use of the diary leads to quality of life improvements over time; and 3) closer examination of the characteristics of users who follow advice and recommendations versus those that don't.

In connection with the above, the guidelines/recommendations already posited as a consequence of this research could be further enhanced and extended to reflect best practice for elongated longitudinal evaluations (which will lead to better understanding of the impact of IT-based solutions) and for evaluation approaches for sustained adaption of UI designs over long periods of time in response to degenerating user capabilities.

Finally, it would be interesting to examine the generalisability of not only our reported guidelines/recommendations but also our reported findings with regards UI design for older adults and the proposed UI adaptation methods/algorithm (see above) across older adults with *other* degenerative disabilities in an attempt to maximise our findings (both current and proposed) to support people with various degenerative disabilities which would otherwise hinder the use of (assistive) technologies.

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Appendix A. Knowledge Elicitation Material

A.1. Ethics Application Approval

| |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| -----Original Message----- |
| <p>From: Apache [mailto:apache@ahric.aston.ac.uk] On Behalf Of C.D.Buckingham@aston.ac.uk Sent: 06 March 2012 10:36 To: Lumsden, Joanna (Jo) Subject: Your Ethics Application has been Approved</p> <p>Your Ethics Application has been APPROVED by the relevant Ethics Committee.</p> <p>Your application's details:</p> <p>Title Of Research: SMART Phases 1-3: Knowledge Elicitation & Design</p> <p>Proposed Start Date: 08 January 2012</p> <p>Chief Investigator Title and Name: Dr Joanna Lumsden</p> |

A.2. Focus Group Consent Form

CONSENT FORM *for* *participation in the research study entitled:* **Developing SMART Technology for Age-Related Macular Degeneration**

Please read this consent form carefully and ask as many questions as you like in order to help you decide whether or not to participate in this research study. Your participation is entirely voluntary and there is no penalty or consequence for choosing not to participate. Feel free to discuss your participation in this study with friends, family members, or with other members of your support network. You are free to ask questions at any time before, during, or after your participation in this research. Even if you decide to participate, you are free to withdraw from the study at any time without penalty.

Dear participant,

The purpose of this consent form is to seek your free and informed consent to participate in a research study entitled “Developing SMART Technology for Age-Related Macular Degeneration”. Please read and make sure you understand all relevant information provided here before you consent to participate. If anything at all is unclear, please don’t hesitate to discuss this study with Lilit Hakobyan (researcher) or Dr. Joanna Lumsden (chief investigator) whose contact details are included at the end of this form.

1. PURPOSE OF THIS RESEARCH STUDY

You are being asked to participate in a research study designed to develop an assistive computer-based mobile application – SMART – to promote independent living and enhanced wellbeing for persons with Age Related Macular Degeneration (AMD). Scientific evidence suggests that there may be a link between nutrition and the onset or rate of progression of AMD. What we propose to do is build a mobile application – that is, a piece of software to run on a mobile phone or similar device – which allows individuals with AMD to accurately and conveniently record what they are eating on a day-to-day basis so that they can be automatically provided with customised dietary advice in order to empower them to make informed dietary choices which could slow down the rate of progression of their AMD. Obviously, since AMD affects individuals' ability to see the screen of a mobile device in many different ways, an ability which also changes over time, it is important that we take this into consideration in designing SMART. At this point in time, we need your help to design this application.

SMART is being developed by a multidisciplinary team of researchers from computer science, psychology, and clinical optometry but it is not possible to develop such an application without turning to the anticipated end users – people like you – for help. We want to learn from you such that SMART is designed to be as good as it can be.

We are asking you to participate in a focus group or individual discussion to talk about what it is like to live with AMD so that we can better understand what we need to do to build a system that will work for you.

Risks

There are no risks associated with participating in this study beyond that of normal, everyday activities.

Confidentiality and Data Storage

All data collected during this study will be kept confidential and will be stored/handled according to the provisions of the UK Data Protection Act

1998. Your responses to any questions will remain anonymous. No one other than members of the research team will have access to the data gathered. Individuals will not be identifiable from the data and will not be identified in any publications related to this research. The data will be stored in a secure fashion.

We thank you very much for your participation.



A.3. Demographic Questionnaire

We would like you to respond to the following demographic questions. The questionnaire will not be linked to your name.

Please mark relevant boxes ☒ for your:

1. Age

☐

60 or under

☐

71 – 80

☐

60 – 70

☐

81 or above

2. Gender

☐

Female

☐

Male

3. Do you have AMD in one or both eyes?

☐

One

☐

Both

4. Do you have Dry or Wet AMD?

☐

Dry

☐

Wet

5. Please write the number of years you have had AMD

A.4. In-Home Observational Study Consent Form

CONSENT FORM

for

participation in the research study entitled:

Developing SMART Technology for Age-Related Macular Degeneration

Please read this consent form carefully and ask as many questions as you like in order to help you decide whether or not to participate in this research study. Your participation is entirely voluntary and there is no penalty or consequence for choosing not to participate. Feel free to discuss your participation in this study with friends, family members, or with other members of your support network. You are free to ask questions at any time before, during, or after your participation in this research. Even if you decide to participate, you are free to withdraw from the study at any time without penalty.

Dear participant,

The purpose of this consent form is to seek your free and informed consent to participate in a research study entitled “*Developing SMART Technology for Age-Related Macular Degeneration*”. Please read and make sure you understand all relevant information provided here before you consent to participate. If anything at all is unclear, please don’t hesitate to discuss this study with Lilit Hakobyan (researcher) or Dr. Joanna Lumsden (chief investigator) whose contact details are included at the end of this form.

1. PURPOSE OF THIS RESEARCH STUDY

You are being asked to participate in a research study designed to develop an assistive computer-based mobile application – SMART – to promote independent living and enhanced wellbeing for persons with Age Related Macular Degeneration (AMD). Scientific evidence suggests that there *may* be a link between nutrition and the onset or rate of progression of AMD. What we

propose to do is build a mobile application – that is, a piece of software to run on a mobile phone or similar device – which allows individuals with AMD to accurately and conveniently record what they are eating on a day-to-day basis so that they can be automatically provided with customised dietary advice in order to empower them to make informed dietary choices which *could* slow down the rate of progression of their AMD. Obviously, since AMD affects individuals' ability to see the screen of a mobile device in many different ways, an ability which also changes over time, it is important that we take this into consideration in designing SMART. At this point in time, we need your help to *design* this application.

SMART is being developed by a multidisciplinary team of researchers from computer science, psychology, and clinical optometry but it is not possible to develop such an application without turning to the anticipated end users – people like you – for help. We want to learn from you such that SMART is designed to be as good as it can be.

We are asking you to allow our researcher (Lilit Hakobyan, whom you have got to know via the focus groups in which you have kindly participated) to observe you as you go about part of your normal daily activities. This would involve inviting her into your home or to accompany you on a typical day out to see how you cope living with AMD. **She would not be assessing you or anything about your life:** she would merely be looking to see what works or is easy for you and what doesn't work or is difficult for you so that when we design SMART, we build a system that *will* work for you. **She will not make any recommendations and/or suggestions about your living arrangements or on any other aspect of your lifestyle.**

We will not observe any aspect of your daily routine which is personal or which you ask us not to. You will be in control at all times. The researcher will take notes but these will not identify you in any way. The researcher will respect your property and privacy at all times. **You are strongly advised to invite a third party whom you know well (e.g., family member, friend, carer, etc.) to be present while the observations are taking place. If you decide to proceed without such a person present, you are required to provide details of a person to contact in case of an emergency.**

Your participation in this study is entirely voluntary and you may end your participation at any time or for any reason without penalty.

Risks

There are no risks associated with participating in this study beyond that of normal, everyday activities.

Confidentiality and Data Storage

All data collected during this study will be kept confidential and will be stored/handled according to the provisions of the UK Data Protection Act 1998. Your responses to any questions will remain anonymous. No one other than members of the research team will have access to the data gathered. Individuals will not be identifiable from the data and will not be identified in any publications related to this research. The data will be stored in a secure fashion.

We thank you very much for your participation.

If you have any questions about this study, please contact us:

Lilit Hakobyan (researcher)

School of Engineering & Applied Science, Aston University, e-Mail:
hakoby11@aston.ac.uk

or

Dr. Joanna Lumsden (chief investigator)

School of Engineering & Applied Science, Aston University, e-Mail:
j.lumsden@aston.ac.uk, Tel: 0121 204 3470

Consent

I, the undersigned, acknowledge that this study has been explained to me to my satisfaction, and I have been given sufficient time to consider my participation in this study. I confirm that I have received, read, and understood all the information above and give my full and informed consent to participate in the study.

I confirm that I was advised to invite a third party (e.g., family member, friend, carer, etc.) to be present while the observations are taking place. I have chosen (☒ please tick as appropriate):

☐ to have a third party present

☐ not to have a third party present

I understand that, if I have chosen not to have a third party present, I am required to provide details of a person to contact in case of an emergency. That person is:

Name of emergency contact person:

Relationship to the
participant: _____

Contact

number: _____

I understand that the observer cannot be held responsible for any issues related to my health and safety.

I understand that my participation in this study is entirely voluntary and that I am free to end my participation in the study at any time or for any reason without penalty. I also understand that any member of the research team can end my participation in the study for financial, scientific, or ethical reasons at any time.

I understand that by signing this form, I give my full and informed consent to the research team to use the data collected for the purpose of this research and any related research that follows.

Name of the participant:

Signature:

Date: _____

Signature of researcher:

Date: _____

CONSENT FORM

for

conducting observational studies in the research study entitled:

Developing SMART Technology for Age-Related Macular Degeneration

I have explained the study to the participant:

Participant's Name: _____

and he/she has agreed to take part. I agree to enter the participant's home at the provided address:

Participant's Address:

I agree to respect the participant's privacy and property at all times.

Name of the researcher:

Signature: _____

Date: _____

Appendix B. Phase 4 Study Material

B.1. PD Consent Form

CONSENT FORM

for

participation in the research study entitled:

Developing SMART Technology for Age-Related Macular Degeneration

Please read this consent form carefully and ask as many questions as you like in order to help you decide whether or not to participate in this research study. Your participation is entirely voluntary and there is no penalty or consequence for choosing not to participate. Feel free to discuss your participation in this study with friends, family members, or with other members of your support network. You are free to ask questions at any time before, during, or after your participation in this research. Even if you decide to participate, you are free to withdraw from the study at any time without penalty.

Dear participant,

The purpose of this consent form is to seek your free and informed consent to participate in a research study entitled “*Developing SMART Technology for Age-Related Macular*

Degeneration". Please read and make sure you understand all relevant information provided here before you consent to participate. If anything at all is unclear, please don't hesitate to discuss this study with Lilit Hakobyan (researcher) or Dr. Joanna Lumsden (chief investigator) whose contact details are included at the end of this form.

1. PURPOSE OF THIS RESEARCH STUDY

You are being asked to participate in a research study designed to develop an assistive computer-based mobile application – SMART – to promote independent living and enhanced wellbeing for persons with Age Related Macular Degeneration (AMD). Scientific evidence suggests that there *may* be a link between nutrition and the onset or rate of progression of AMD. What we propose to do is build a mobile application – that is, a piece of software to run on a mobile phone or similar device – which allows individuals with AMD to accurately and conveniently record what they are eating on a day-to-day basis so that that they can be automatically provided with customised dietary advice in order to empower them to make informed dietary choices which *could* slow down the rate of progression of their AMD. Obviously, since AMD affects individuals' ability to see the screen of a mobile device in many different ways, an ability which also changes over time, it is important that we take this into consideration in designing SMART.

SMART is being developed by a multidisciplinary team of researchers from computer science, psychology, and clinical optometry but it is not possible to develop such an application without turning to the anticipated end users – people like you – for help. Only YOU know what it is like to live with AMD. Only YOU know what you would like or not

like in an application such as SMART. We want to learn from you such that SMART is developed to be as good as it can be.

We are asking you to join our design team as an equal and valued member in order to help us actually design the SMART application. You would be required to attend a series of design meetings where we would look to you to contribute as an expert in living with AMD to the design process. The design will be done on paper, using standard office stationary so no technical expertise or experience is required. You would be required to work as part of the team to come up with a design which we will then build into a real application. Design sessions would last no more than 2 hours each and would be held in at a venue comfortable for you.

Your participation in this study is entirely voluntary and you may end your participation at any time or for any reason without penalty.

Risks

There are no risks associated with participating in this study beyond that of normal, everyday activities.

Confidentiality and Data Storage

All data collected during this study will be kept confidential and will be stored/handled according to the provisions of the UK Data Protection Act 1998. Your responses to any questions will remain anonymous. No one other than members of the research team will have access to the data gathered. Individuals will not be identifiable from the data and will not be identified in any publications related to this research. The data will be stored in a secure fashion.

We thank you very much for your participation.

If you have any questions about this study, please contact us:



B.2. PD Study Questionnaire

De-Brief Questionnaire

for the research study entitled:

Developing SMART Technology for Age-Related Macular Degeneration

Thank you for your participation in our study. This questionnaire is designed to find out your thoughts on your participation in the study. Your responses will remain anonymous.

- 1. Have you ever participated in any type of research study before?**
(Research studies also include clinical trials) (Please circle)

Yes

No

If **No**, please skip to Question 3.

- 2. Did you find this study to be any different to ones you have previously been involved with? (Please circle)**

Yes

No

If **Yes**, please briefly explain your answer in the space provided.

| |
|--|
| |
|--|

3. **Did you enjoy taking part in this study?** (Please think about each component of the study and indicate how much you enjoyed each one independently by circling the appropriate response)

| | Didn't Enjoy at All | Only Enjoyed a Little | Neutral | Enjoyed Quite a Lot | Enjoyed Very Much |
|-----------------|------------------------|-----------------------------|---------|---------------------------|-------------------------|
| Focus Groups | 1 | 2 | 3 | 4 | 5 |
| In-Home Studies | 1 | 2 | 3 | 4 | 5 |
| Design Sessions | 1 | 2 | 3 | 4 | 5 |

4. **Do you feel you have been able to make a valuable input to the study?** (Please think about each component of the study and indicate how much you felt you were able to contribute to the study via the component by circling the appropriate response)

5.

| | Didn't Contribute at All | Only Contributed a Little | Neutral | Contributed Quite a Lot | Contributed Very Much |
|--------------------|--------------------------------|---------------------------------|---------|----------------------------|--------------------------|
| Focus Groups | 1 | 2 | 3 | 4 | 5 |
| In-Home Studies | 1 | 2 | 3 | 4 | 5 |
| Design Sessions | 1 | 2 | 3 | 4 | 5 |

6. How useful do you think each of the component parts of the study were? (Please think about each component of the study and indicate how important it was to the study in terms of understanding what it is like to live with AMD and designing technology to meet the needs of someone with AMD by circling the appropriate response)

| | Not Important at All | Only a Little Important | Neutral | Quite Important | Very Important |
|--------------------|----------------------------|-------------------------------|---------|--------------------|-------------------|
| Focus Groups | 1 | 2 | 3 | 4 | 5 |
| In-Home Studies | 1 | 2 | 3 | 4 | 5 |
| Design Sessions | 1 | 2 | 3 | 4 | 5 |

7. How easy did you find it to participate in the various sessions?
(Please circle one number for each method)

8.

| | Very Difficult | A Bit Difficult | Neutral | Quite Easy | Very Easy |
|-----------------|-------------------|--------------------|---------|---------------|--------------|
| Focus Groups | 1 | 2 | 3 | 4 | 5 |
| In-Home Studies | 1 | 2 | 3 | 4 | 5 |
| Design Sessions | 1 | 2 | 3 | 4 | 5 |

9. Do you feel you have established a good working relationship with the researcher? (Please circle)

Yes

No

10. Please comment on your opinion of the end design you contributed to.

11. Do you think other people with AMD could benefit from the final design?

12. What did you learn or gain from this experience that was unexpected?

13. Have you changed your attitude about research studies in any way as a result of this study?

14. Please comment generally about your feelings about your involvement in this study and how the study was conducted.

15. Please add any feedback or recommendations you might have.

B.3. Post PD Interview Protocol

Participants

Did you enjoy the design meetings?

Was the meeting space suitable for the design sessions?

Was the aim of the design meetings clear?

How easy was it to contribute to the discussions during the design meetings?

How easy was it to contribute to the paper prototype design?

The pace of this workshop was appropriate.

The workshop activities stimulated my learning.

The design meetings were a good way for me to learn about technology.

What was the most interesting part?

What was the most confusing part?

What was least valuable about the design meetings?

What was most valuable about the design meetings?

What was challenging about participating in design meetings?

What could we do to improve the actual design process?

What advice would you give in order to improve these sorts of sessions for people with visual impairments?

Do you have any suggestions for improvement?

For the design:

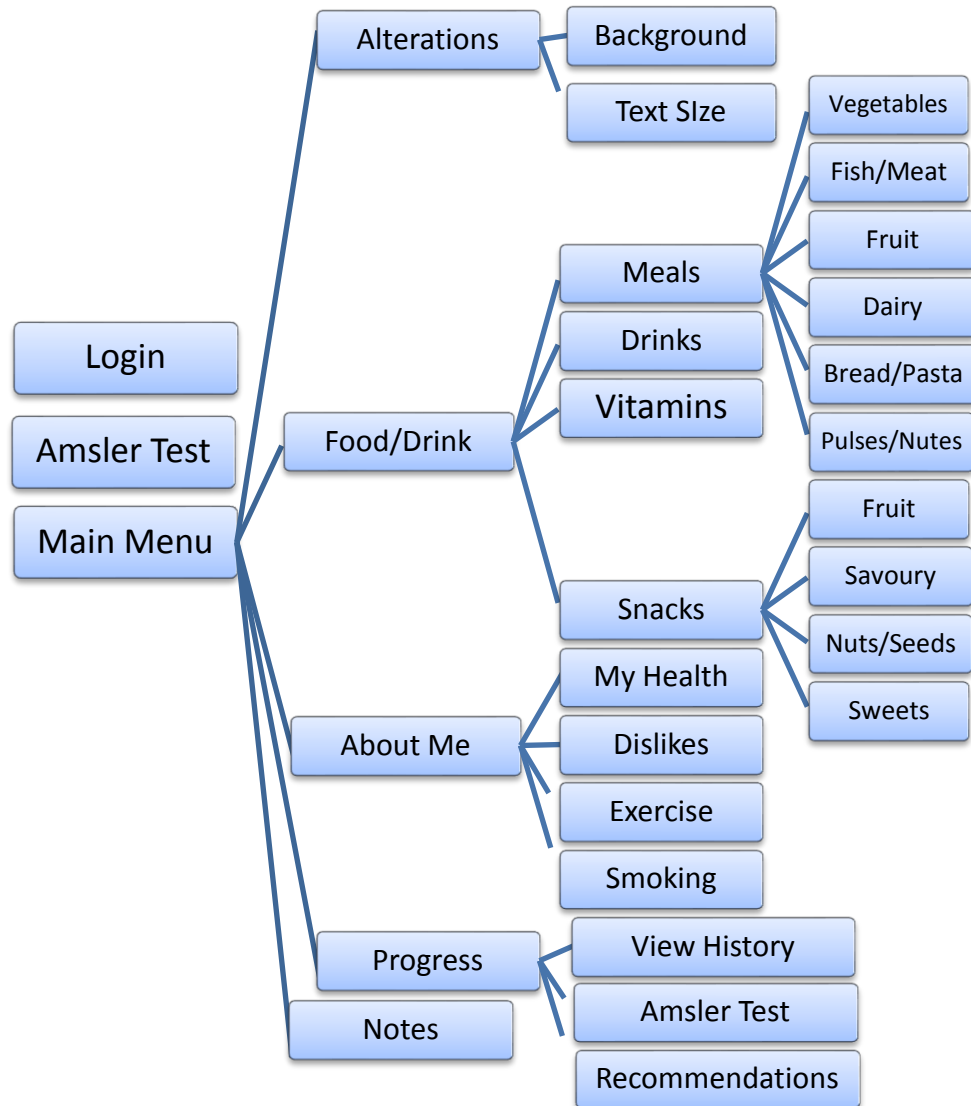
Does this make sense to you?

Are you able to figure it out?

What changes would you make to them?

Do you think you would use this?

Appendix C. The Diet Diary Application's Structure



Appendix D. Evaluation Study Material

D.1. Ethics Application Approval

Published on Aston University Ethics Committee (<https://www.ethics.aston.ac.uk>)
Home > My Applications

Reference No.

PhD Student Ethics Application
628

Title of Research

SMART: User Acceptance Study

Name

Dr Jo Lumsden

Date

27/05/2014

School

Engineering and Applied Science

State:

Approved

Source URL: <https://www.ethics.aston.ac.uk/my-applications>

Research Study

Developing SMART Technology for Age- Related Macular Degeneration



Invitation

You are being invited to participate in a research study designed to evaluate an assistive computer-based mobile application – SMART – designed and developed with and for persons with Age Related Macular Degeneration (AMD).

Details of the Study

Scientific evidence suggests that there may be a link between nutrition and the onset or rate of progression of AMD. What we have built is a mobile application – that is, a piece of software to run on a tablet device (or similar) – which allows individuals with AMD to accurately and conveniently record what they are eating on a day-to-day basis so that that they can be automatically provided with customised dietary advice in order to empower them to make informed dietary choices which could potentially slow down the rate of progression of their AMD.

SMART has been developed by a multidisciplinary team of researchers from computer science, psychology, and clinical

optometry with direct input from people with AMD, some of whom acted as co-designers for the application itself. It is now really important that we evaluate the use of SMART with its intended user group – people like you.

We want to learn from your experience with SMART such that it can be refined to be as good as it can be.

We are asking you to participate in a focus group. These will be small groups of people with AMD (like yourself) who will come together so that we can show you our SMART application and talk about it to help us understand your initial reaction to it. Focus group sessions will be held in a location that is comfortable for you (either at Aston University or a local coffee shop to minimise the need for you to travel). We would be willing to reimburse your travel expenses. Individual sessions will not last longer than 2 hours.

We thank you very much in advance for your participation.

If you have any **questions**, please contact us:

Lilit Hakobyan (researcher)



D.3. Phase 5 Study Consent Form

CONSENT FORM

for

participation in the research study entitled:

Developing SMART Technology for Age-Related Macular Degeneration

Please read this consent form carefully and ask as many questions as you like in order to help you decide whether or not to participate in this research study. Your participation is entirely voluntary and there is no penalty or consequence for choosing not to participate. Feel free to discuss your participation in this study with friends, family members, or with other members of your support network. You are free to ask questions at any time before, during, or after your participation in this research. Even if you decide to participate, you are free to withdraw from the study at any time without penalty.

Dear participant,

The purpose of this consent form is to seek your free and informed consent to participate in a research study entitled “*Developing SMART Technology for Age-Related Macular Degeneration*”. Please read and make sure you understand all relevant information provided here before you consent to participate. If anything at all is unclear, please don’t hesitate to discuss this study with Lilit Hakobyan (researcher) or Dr. Joanna Lumsden (chief investigator) whose contact details are included at the end of this form.

1. PURPOSE OF THIS RESEARCH STUDY

You are being asked to participate in a research study designed to evaluate an assistive computer-based mobile application – SMART – designed and developed with and for persons with Age Related Macular Degeneration (AMD). Scientific evidence suggests that there *may* be a link between nutrition and the onset or rate of progression of AMD. What we have built is a mobile application – that is, a piece of software to run on a tablet device (or similar) – which allows individuals with AMD to accurately and conveniently record what

they are eating on a day-to-day basis so that that they can be automatically provided with customised dietary advice in order to empower them to make informed dietary choices which *could* potentially slow down the rate of progression of their AMD.

SMART has been developed by a multidisciplinary team of researchers from computer science, psychology, and clinical optometry **with direct input from people with AMD**, some of whom acted as co-designers for the application itself. It is now really important that we evaluate the use of SMART with its intended user group – people like you. We want to learn from your experience with SMART such that it can be refined to be as good as it can be.

We are asking you to use SMART for a week as part of your daily routine to help us identify how easy it is to use and determine anything you would like to see changed in the design of the application. We would also like to determine how useful you found it. You will be provided with a tablet device with SMART. We will train you on a one-on-one basis in how to use SMART, set it up to be personalised to your preferences, and then allow you to “play” with SMART so you can get used to it and ask any questions. Once you are happy to proceed, you will be asked to use the tablet device to record your daily food intake so that SMART can give you some suggestions for improving your diet to help you with your AMD.

We will NOT be assessing your diet or judging you on your diet. We will be looking to see whether you used SMART, how easy it was to use, did the personalisation work for you, and how useful did you find it and the dietary recommendations. In other words, we want to know what YOU thought about the application so that we can improve it so that it *will* work for you. We will meet with you at the start of the week to set things up and again at the end of the week to get your feedback.

Your participation in this study is entirely voluntary and you may end your participation at any time or for any reason without penalty.

Risks

There are no risks associated with participating in this study beyond that of normal, everyday activities.

Confidentiality and Data Storage

All data collected during this study will be kept confidential and will be stored/handled according to the provisions of the UK Data Protection Act 1998. Your responses to any questions will remain anonymous. No one other than members of the research team will have access to the data gathered. Individuals will not be identifiable from the data and will not be identified in

any publications related to this research. The data will be stored in a secure fashion.

We thank you very much for your participation.

If you have any questions about this study, please contact us:



D.4. Phase 6 Thematic Analysis: Initial Data Extracts

| Data Extracts | Coded As |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>"I had an assessment as well, memory test and it scattered me quite a bit, it was ridiculous you were supposed to follow a pattern of this and patten of that, and I came away from it more irritable than when I was going in [...] I didn't think I did very well on drawing the lines one but I think I did very well in some things general. But no one said anything to me [...]"</i> | <ol style="list-style-type: none"> 1. Lack of information available to patients 2. Clear instructions & adequate information required 3. Uncertainty can cause distress and anxiety |
| <i>"Oh I don't find it difficult to use, I just think be patient, don't lose the plot [the researcher] would say, as I say I have been into Google – it can be done, it can be sorted out – just don't panic – keep going!" (participant 3).</i> | <ol style="list-style-type: none"> 1. Shows strength of character 2. Determined to succeed 3. Explored the tablet for other purposes 4. Managed challenges/errors well 5. Didn't find the app difficult to use 6. Evidence of self-efficacy |
| <i>"It's up to you, it's up to you, the choice is yours. You can go out or stay at home and keep twiddling my thumbs. I was busy like you when I was 30 and it does get better. You need something to register, to keep your brain cells busy".</i> | <ol style="list-style-type: none"> 6. Stimulates learning 7. Keeps brain active 8. Acceptance of the condition 9. Affirmative and hopeful attitude 10. Shows strength of character |
| <i>"If you don't do it for you, do it for the community!" (participant 6).</i> | <ol style="list-style-type: none"> 3. Keen to help others 4. Considering others' needs 5. Determined to succeed |
| <i>"I think you have to have a routine with it, especially if you make your mind up teatime" (participant 5).</i> | <ol style="list-style-type: none"> 3. Importance of routine 4. Usage style |
| <i>"I prefer to do it this way [writing on the paper first], otherwise you can't remember what's in your brain. If you try to remember what you had ... ok you could do it after every time you eat, but I prefer this way." (participant 6).</i> | <ol style="list-style-type: none"> 4. Usage style 5. Importance of routine 6. Health concern - memory |
| <i>"I'm getting on alright but not good enough for me [talking about the tablet use]. I have high expectations of myself [laughs] and I think you have as well high expectations." (participant 1).</i> | <ol style="list-style-type: none"> 5. Determined to succeed 6. Evidence of self-efficacy 7. High expectations 8. Considering researcher's expectations |
| <i>"Technology is a great thing, and it is very important to me, because you [the researcher] believed in me, so you must see something in me, and because I did have an enquiring mind [...] but I will get back on that again, I know I will, I have to remind myself that I can eat healthy even if it is just for this project."</i> | <ol style="list-style-type: none"> 1. Determination 2. Positive feedback |
| <i>"It depends how open minded you are with technology. Really I suppose we all have different motivations. Because I am secretary for AMD club, now I have got an investment in this in that we need something like this to help people, it's the biggest cause of visual impairment here I the UK." (participant 5)</i> | <ol style="list-style-type: none"> 1. Depends on mind set 2. Attitude towards technology 3. Motivation of use 4. Benefits gained |

| | |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>"It [the app] would give you some hope, whereas with this [shows doctor's appointment note] you would just get medically messed with, whereas with this you would have some hope of directing your own health. It's a self-help. It would only do good and make you feel emotionally really good."</i> (participant 3) | <ol style="list-style-type: none"> 1. Positive attitude 2. Self-monitoring 3. Gives hope 4. Improved well being |
| <i>"You are trying to help yourself. It raises your awareness about what you take it's an eye-opener so [friend] and I could use this. I think it motivates you and I think with our eyes we would be more motivated to use this. But I suppose what it is doing it is helping someone else who will be diagnosed with AMD."</i> (participant 2) | <ol style="list-style-type: none"> 1. Helpful to people with AMD 2. Raises awareness 3. Self-monitoring 4. Motivational |
| <i>So if anyone says 'oh it's going to take me hours', once you get used to it takes no longer than that. You have to be determined if you want to be independent and all that. I would say to people, Look don't panic about it. Once you get used to it, it takes no more than ten minutes to do it."</i> | <ol style="list-style-type: none"> 5. |

Pride in Taking Part

| Data Extracts | Coded As |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>"I will keep documents [project related] to show people what I have done, and you can keep mine if it's any good for you [...]"</i> | <ol style="list-style-type: none"> 1. Full of pride |
| <i>"The younger people who are going to use this [the app] the ophthalmologist will say it's in your hands and of you go, go and use this. They perfected this camera that will show you have amd, so after that they can use this application to improve their diet. Pioneers we are pioneers."</i> | <ol style="list-style-type: none"> 1. Full of pride 2. Recognises benefits of the app 3. Considering others needs 4. Improves self-esteem |
| <i>"I found this fascinating, to be part of this and when things worked for me, it's a shame a lot of things happened lots of funerals and other sad things, but it has been a remarkable experience."</i> | <ol style="list-style-type: none"> 1. Full of pride 2. Delight in participation |
| I am the poster girl, personal assistant, put PA in Shirley, That's was great when I got Google I thought first panic, then I said no here we go, I can sort this out no panic, I should get people to book appointments I will probably get people ringing me [name] can you help?" | <ol style="list-style-type: none"> 1. Full of pride 2. Enjoyed exploring the app 3. Help others |
| This project is the best thing that has happened to mum. She talks about this everywhere we go. I think everyone in the family knows you [the researcher] by now. She loves going on and on about you and this project, even at my son's wedding. Thank you for being so kind to her." | <ol style="list-style-type: none"> 1. Full of pride 2. Benefits of the app |

Improved Memory

| Data Extracts | Coded As |
|---------------|----------|
|---------------|----------|

| | |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------|
| "I think you have to have a routine with it, especially if you make your mind up teatime –ish. But I have to tell you it makes wonders to your memory." | 1. Usage style 2. Impact – improved memory |
| "I prefer to do it this way [showing the application], otherwise you can't remember what's in your brain, when the doctor asks you. If you try to remember what you had ... ok you could do it but I don't have to with this [the application]." | 1. Usage style 2. Health concern - memory |
| "It all depended how I felt myself, If I was really well I could remember all the things I had it wasn't difficult to remember what I ate because it made me think, yes, it made me think. I could, or times I would not do it quick and it irritated me I wanted something simple on my mind, but when my memory clicked I did master it, I thoroughly enjoyed it." | 1. Keen to learn 2. Usage style 3. Health concern – memory 4. Mood impacted app usage |

Behaviour change

| Data Extracts | Coded As |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------|
| "I have started drinking more water because of this". | 1. Behaviour change 2. Positive impact of the app |
| "Funnily enough I looked, I don't enough fruits so when I saw grapes on my recommendation list, I started eating grapes and I shall continue doing so. I get on quite well with grapes and hope to make it a regular thing. I should also eat a lot of fruits I know now that I don't." | 1. Behaviour change 2. Positive impact of the app 3. Followed recommendations |
| "Oh you are a little genius you are [referring to the app], I do really work on my nutrition now". | 1. Behaviour change 2. Positive impact of the app |
| "Now the other day I did not realise I did not have zinc ... I used to eat bananas but then stopped, so that was a great thing to discover that I do not eat enough zinc." | 1. Behaviour change 2. Positive impact of the app 3. Followed recommendations |
| "You know what's really interesting, since I have been checking my history [app entries] I did not realise how little I was eating, so no wonder am so week so I am determined to improve my diet". | 1. Positive impact of the app 2. Keen to improve diet 3. Found the app informative |
| "Yes I did recommendations, and I did notes, and I could see where it was saying different vitamins I needed and that I was having pumpkin seeds because it was recommending it and so I gave a go. | 1. Used recommendations and notes 2. Positive impact of the app 3. Behaviour change 4. Health concern - memory |
| "The benefit I found was it made me sit down and list everything I was eating and drinking so it regimented me into thinking logically right what did I eat today and reminded me if I did not eat or drink enough, though drinking primarily, so it concentrated my mind on what I was eating or drinking because we never do enough, so it's a discipline of doing it. I get frustrated when I don't drink enough and my wife reminds me to go and have a drink so this is great." | 1. Usage style 2. Positive impact of the app 3. Keen to improve diet 4. Found the app informative |

| | |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>“I eat well now and its only when I scribbled down for this thing [the app] I realised I was eating hardly anything, its only when I noted down important because like you said the important issue was the nutrition [...] I was looking at what I had [...] I hardly had any fruit and then I thought well I am only having cereal and a piece of toast and don't have anything constructive with it [...] so I need to do something, haven't I? [...]"</i> | <ol style="list-style-type: none"> 1. Behaviour change 2. Positive impact of the app 3. Keen to improve diet 4. Considering others needs |
| <i>“I tend to have peanuts, it keeps recommending almonds and hazelnuts so I will change to it, if that's what they are telling me it must be good for me.”</i> | <ol style="list-style-type: none"> 1. Behaviour change 2. Keen to improve diet |
| <i>“[...] I am also determined to eat well to look after myself, so if I eat well and look after myself I can do it, wouldn't it be marvellous!"</i> | <ol style="list-style-type: none"> 1. Keen to improve diet 2. Positive impact of the app 3. Recognises benefits of behaviour change |

Interest in others

| Data Extracts | Coded As |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>“So it takes my ignorance for somebody to improve, I can live with that.” I need to keep hard copy anyway for my doctor.”</i> | <ol style="list-style-type: none"> 1. Usage style 2. Interest in others |
| <i>“I have talked about this project with other members [from AMD club] and there are a lot of them interested in taking part [laughing] they can talk to me.”</i> | <ol style="list-style-type: none"> 1. Interest in others 2. Snowball effect 3. Full of pride 4. Handled challenges well 5. Improved self-esteem |
| <i>“There are couple people that I know would find this really useful who aren't really eating healthy so this would concentrate their mind. I had lots of people asking me how this was working, what it was telling me, and what recommendations I was receiving, I even wrote down some of it [recommended food] and handed out to my friends and they said they would like something like this too. It's this idea that something is being done its comforting to know, the main thing they liked is that it gives recommendations they can eat, so it's very encouraging to receive recommendations, it gives them a feel, so yes my friends really liked it.”</i> | <ol style="list-style-type: none"> 1. Importance of personalised recommendations 2. Motivational factor 3. Concerned about others |
| <i>“I think also having other friends who use it if you met or if you all were part of the macula meeting then you could use part of the meeting to discuss how you got on with it and your progress and so on. You could actually speak to others about your progress. Or involve people who would suggest recipes to cook. I think maybe link to the recipes would be really good.”</i> | <ol style="list-style-type: none"> 1. Keen to help others 2. Considering others needs 3. Prospect of being connected/keeping in touch 4. Comparing performance/progress 5. Suggestion – recipes suggestion |
| Benefits of the Application | |
| <i>“I have all my appointments here, its brilliant, look I have your appointment here and my doctor's one. All the things that I have to remember goes here.”</i> | <ol style="list-style-type: none"> 1. Informative 2. Explored the app –used 'Notes' 3. Recognised benefits of the app |

| | |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| People say and this lady left school at 14 you know, so I have to self-educate, I can't believe I am saying this." | 1. Stimulates learning 2. Fulfilled experience |
| "I hope this [the app] can help me to go back on to the computer, it's like my new toy, I am determined to master it; I will not be defeated. What fascinates me is that you can enter this information feed in and withdraw I am much more proud of myself because before I would be oh I will read a magazine but now, that is a bigger interest altogether [...] I was thinking that maybe after Christmas going for computer classes so I can go back on to computer, that would be marvellous, so I am determined [...]" | 1. Stimulates learning 2. Changed outlook of life 3. Fulfilled experience 4. Determined to succeed 5. Motivational factor 6. Improved self-esteem |
| "[...] and I think my memory is not as bad as it used to be, you know I think it's improving." | 1. Recognised benefits of the app 2. Impact – improved memory |
| "Oh I liked it! It was an achievement I thought, because I never used computers or tablets of any description before you know, I wasn't too adventures with it ... But I got Google, which was great. It was dangerous, but I loved it! Oh I had another thing coming up the other day but I got rid of it!" | 1. Recognised benefits of the app 2. Stimulates learning 3. Explored the use of app 4. Fulfilled experience 5. Improved self-esteem |
| "It concentrates your mind as to what you are actually eating and drinking, and when I haven't been drinking enough couple of days ago I could go back and check and see that I haven't been drinking enough. I got on quite well with this. And so it concentrates your mind on what you are eating and drinking, or what you shouldn't be eating, yeah it's great, I really enjoyed it." | 1. Recognised benefits of the app 2. Successfully monitored diet 3. Keeps brain active 4. Raises awareness |
| "I think if you were diagnosed with AMD, then this app would have made you proactive at least. With this, if you were given this you would think I am taking a proactive approach and doing something for my health." | 1. Recognised benefits of the app 2. Raises awareness 3. Encourages proactive approach |
| "Because of this I am back to reading heavy stuff, so thank god for it, I am pleased about that and also I rung about joining the computer club I told you [...] but they said they would [enrol] in the new year, but I thought by then I would be more irritable with myself once you take this away. I really should be learning shouldn't I?" | 1. Stimulates learning 2. Changes outlook of life 3. Adverse/destructive impact of withdrawal |
| "I was just putting in 'All about me' and I put all my tablets." | 1. Used 'All about me' option |
| well I am not so bad, there are a lot of other ladies who are not eating enough [...]" (participant 1) | 2. Considered others |
| "It was a great fun. Because I never done anything like this, I am just an ordinary factory worker going into this technology world. I thought it was going to be daunting or me, but it turned out to be very enjoyable experience form. I have learnt so much [laughing] never thought I would say this in my age." | 1. Positive use 2. Stimulates learning |

| | |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------|
| <i>"I am back to reading heavy stuff, so thank god for I am pleased about that, and also I rung about joining the computer club I told you, they couldn't take me now because they in the middle of session, but they said they would in the new year, but I thought by then I would be more irritable with myself once you take this away and I don't get to see you."</i> | <ol style="list-style-type: none"> 1. Stimulates learning 2. Withdrawal from study |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------|

App Feedback – Ease of use

| Data Extracts | Coded As |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>"It was just easy to use, very pleased. Thumbs up."</i> | <ol style="list-style-type: none"> 1. Easy to use 2. Enjoyed the experience |
| <i>"I found it easy enough."</i> | <ol style="list-style-type: none"> 1. Easy to use |
| <i>"It was fairly easy to use. Yeah once you got the hang of it, it was easy to use."</i> | <ol style="list-style-type: none"> 1. Easy to use |
| <i>"Good! We certainly made the right choices; the only thing I would say is the icons on the tablet side are small. But the whole thing that we set up is great! Can't fault it, I can't fault it, so easy to use."</i> | <ol style="list-style-type: none"> 1. Easy to use 2. Hardware issues 3. Substantiated choices/decisions design |
| <i>"Well if you were somebody like , me who wasn't into something like technology – I don't love it I am never going to love it, I would say it's quite convenient to use because one the tablet is easy to use, there isn't too much to do and I could do it in a very short time which is at this moment in time quite useful and plus I lead a very social life so when it comes to a certain time I think right that's me done, so done everything now I <i>will try to watch TV</i>. So I do not want something that is going to take hours to do, and this was just that – easy to use"</i> | <ol style="list-style-type: none"> 1. Easy to use 2. Quick to learn |
| <i>"Yes, everything we said it was going to be it is, all the options, everything is great!"(participant 5).</i> | <ol style="list-style-type: none"> 1. Substantiated choices/decisions design 2. Easy to use |
| <i>I don't have to write things down and it records it straight away – Brilliant.</i> | <ol style="list-style-type: none"> 1. Advantage of use |
| <i>It's certainly easier then writing on a paper if you'd asked me to write it down my diet every day I might get really bored doing it every day, but this one took only a few minutes to do it, I did forget the other night, but as far as time is concerned It's very easy to use I didn't find it tiresome or anything liked that.</i> | <ol style="list-style-type: none"> 1. Easy to use 2. Quick to do |
| <i>"it is easy to use, I find it didn't take me long to get into the swing of it."</i> | <ol style="list-style-type: none"> 1. Easy to use |
| <i>"I remember bringing this up months ago when we were doing the designs, this could be a good diet thing as well not just for your AMD."</i> | <ol style="list-style-type: none"> 1. Other benefits of the app |
| <i>"When I first started with computers I hated them I couldn't stand them but now ... they are addictive I can't without my tablet."</i> | <ol style="list-style-type: none"> 1. Change of attitude 2. Found addictive |
| <i>"Because you are only using your hands, it is really easy to use; you can be mobile, fairly straightforward so I can't think why it would be difficult to use."</i> | <ol style="list-style-type: none"> 1. Easy to use 2. Advantages of 'mobile' technology |

| | |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>"People are really interested in what I am doing as part of this project, which is great. The thing is, if we can do anything to help you that's great, and you are looking at a broader spectrum of people."</i> | <ol style="list-style-type: none"> 1. Improves self-esteem 2. Supportive of the researcher |
| <i>"It's like god send, absolutely brilliant. When I see my hairdresser she booked everything for me. Yes it's the fact that I feel inadequate without technology, so maybe I can do all this things." (</i> | <ol style="list-style-type: none"> 1. Fulfilled experience 2. Advantages of technology 3. Possible adverse impact of withdrawal |
| <i>"It's not difficult, it's a question of it has to click in here [showing her head]. I just need to go to a class and be in the same boat as everyone else. I don't mean wonderful brains and all that because it's there, so I really need more classes to get more feedback."</i> | <ol style="list-style-type: none"> 1. Not difficult to use 2. Requires more help/interaction/feedback 3. Would benefit from teamwork |
| <i>"It was fine, it was interesting, I was surprised I could use it; one thing I was surprised is when I looked at the least of food entered at the end of the day I was quite surprised at how much I had eaten ... When you look at the list you think did I consume all this?"</i> | <ol style="list-style-type: none"> 1. Monitored diet 2. Easy to use 3. Surprised found easy 4. Reflected on diet |
| <i>"it was very simple, if it was anything more than that I would have to get somebody to help me, once I got the hung of it, it was simple to use, and with a bit of common-sense you could read the manual I found the keyboard easy, when I first saw it I thought god how am I going to use it but it was fairly easy to use ... but the keyboard didn't always come out but I figured out once you the thing it came out so it was fairly easy to pick up once you understood how the thing worked, so I did not have any problems putting the thing on and off. So it seemed to work for me."</i> | <ol style="list-style-type: none"> 1. Easy to use 2. Keyboard issues |
| <i>"I cant think of anything, I thought it was fairly simple program."</i> | <ol style="list-style-type: none"> 3. Easy to use |
| <i>"I did have difficulties to start with but quite honestly I think it is easier than computers, because after a few trial and errors I think I have mastered it [laughing]. It was fun and easy to use. Also, you just pick it up so it gives me some kind of notion to buy one like this. It is easy you can take it with you and I can see everyone using them my grandchildren, so if you come back by Christmas I might have one."</i> | <ol style="list-style-type: none"> 1. Easy to use 2. Advantages of tablet device 3. Same as grandchildren |
| <i>"Oh the first couple of days to get stragglng but no difficulties at all, soon I could get myself out of troubles, and that was a great feeling, indeed."</i> | <ol style="list-style-type: none"> 1. Easy to use 2. Overcome difficulties |
| <i>"I found it very easy, no problems at all, at the beginning obviously not so as I have never used anything of this type before, but once I got used to it, it was great, no problems at all."</i> | <ol style="list-style-type: none"> 1. Easy to use |
| <i>"No, I just found it quite easy, when I did something I could take it back, especially when you showed me the bits and bobs it was really easy."</i> | <ol style="list-style-type: none"> 1. Easy to use |
| <i>"Once I got the hang of it, it went really well, provided I did not log myself out. I have never used a tablet or a smartphone or a computer before, but this was great, very easy to use indeed."</i> | <ol style="list-style-type: none"> 1. Ease to use 2. Issues with return |

Suggestions for improvement

| Data Extracts | Coded As |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>"What I started doing is entering food in big blocks but I forgot to enter in the evening so when I came back on morning to enter it, it was empty [...] It would be nice to be able to go back one day".</i> | 1. Possibility to record for previous days |
| <i>"I want to talk to technology so its verbal, if I get to study something too long I get tired"</i> | 1. Speech recognition 2. Short attention span |
| <i>"It's up to you, it's up to you, the choice is yours. You can go out or stay at home and keep twiddling my thumbs. I was busy like you when I was 30 and it does get better. You need something to register, to keep your brain cells busy".</i> | 1. Stimulates learning 2. Keeps brain active 3. Acceptance of the condition 4. Affirmative and hopeful attitude 5. Shows strength of character |
| <i>"When you come up with recommendations, the list might be daunting It's the appearance of it ... everything else is quite pictorial and user friendly. Maybe you could have different colours, but what about people who are colour blind?"</i> | 1. Recommendation list not engaging 2. Considering others' needs 3. App is user friendly |
| <i>"I was really interested to see what I would eat, but the list is not engaging enough – would you think of this? Maybe you could have a picture of the food instead of writing it down?"</i> | 1. Recommendation list not engaging 2. Pictures for recommendations 3. Keen to monitor diet |
| <i>"Only if it was in darker print, and maybe at the end of recommendations put something like – "This is in your best interest to take notice of what we telling you", like a caption to remind them that it is not silly stuff but important."</i> | 1. Motivational quote 2. Personalised communication |
| <i>"You know you could have different sounds for notifications pings for different food categories to remind people to have it."</i> | 1. Notifications for recommendations 2. Alert sounds |
| <i>"I want to get and look at that [recommendations] because I get rewards [referring to games] and if the progress said: "Well done [name] and so on."</i> | 1. Personalised communication 2. Rewards for adhering to the recommendations |
| <i>"I would also like sounds ... this size [7 inch] was also not manageable and the buttons on the tablet are ridiculous you can't find them to switch on/off. It might sound duff, but I lost this the other day and could not find it."</i> | 1. Hardware issues – small button size 2. 7 inch tablet too small 3. Sound feedback |
| <i>"I need somebody who was using this with me."</i> | 1. Call for encouragement/backing 2. Comparing performance |
| <i>"It's the awareness of the nutrition, it's not good to read on journal you need to eat the ... the ... the ... the, and I think everybody in my position must feel the same, the Women's or something [referring to the Womens magazine] might say eat this and that, but then after few days you gonna throw the thing out and you are left with nothing. There are so many people who live on their own and they don't go out to eat. The nutrition is the most important thing, [...] It's the neglect of yourself you need to tackle."</i> | 1. Awareness of nutrition 2. Considering others' needs 3. Advantages of technology |
| <i>"Would be great, if it [the app] could help plan meals."</i> | 1. Help planning meals 2. Recipes recommendations |

Concerns

| Data Extracts | Coded As |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>"[...]I can't break it [the tablet]? Good I can't break it. Good lord, so simple [...] I can roll this in a skirt and take it with me for my holiday [...] I will get on alright!"</i> | <ol style="list-style-type: none"> 1. Easy to use 2. Fear of breaking the tablet 3. Using out-of-doors |
| <i>"I can't believe I could not see it [volume button on the tablet], of course, good lord, that is marvellous, and are you sure if I take this with me to holiday ... I would be worried if something happens ... its marvellous I will sit out and play with this"</i> | <ol style="list-style-type: none"> 1. Fear of breaking the tablet 2. Hardware issues – small button size 3. Using out-of-doors |

Hardware issues

| Data Extracts | Coded As |
|-----------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------|
| <i>"I kept hitting the return button and logging out so I had to log back in again which was annoying as I then got slower at going back."</i> | <ol style="list-style-type: none"> 1. Return button logged out 2. Slowed down the process 3. Found annoying |
| <i>"I found this [10.1 sized tablet) easier and better to use."</i> | <ol style="list-style-type: none"> 1. Found the 7inch too small |
| <i>"Absolutely brilliant! Much easier with the pen [stylus], you are not making a lot of mess on the screen. I found it no problem, brilliant."</i> | <ol style="list-style-type: none"> 1. Stylus improved ease of use |
| <i>"The only thing I did have trouble in the early days was hitting the return button on the tablet that kept logging me off."</i> | <ol style="list-style-type: none"> 1. Return button logged out 2. Slowed down the process |

D.5. User Manual

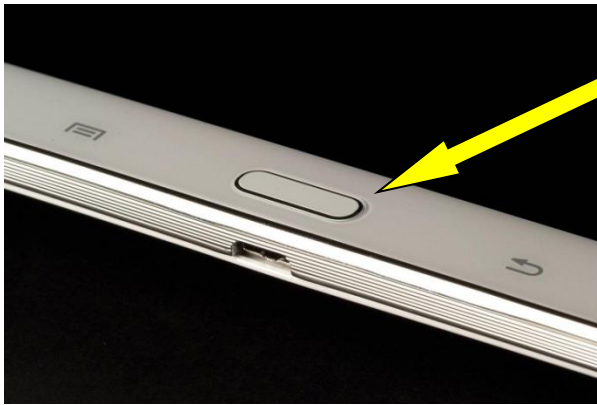
Your Tablet at a Glance

The following illustration outlines your tablet's primary external features and buttons.

Prior to using the tablet, its necessary charge the battery.

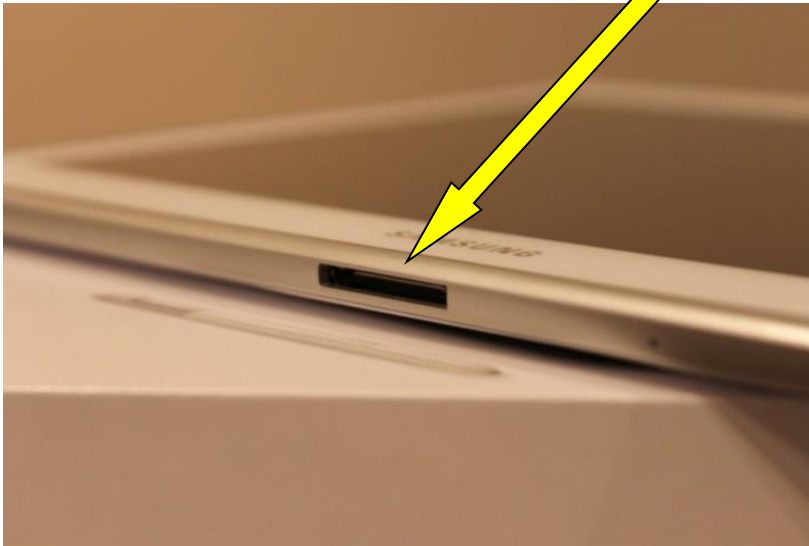


Lightly press the Power Key to switch the tablet on and off.



Home Key – press to return to tablet home page.

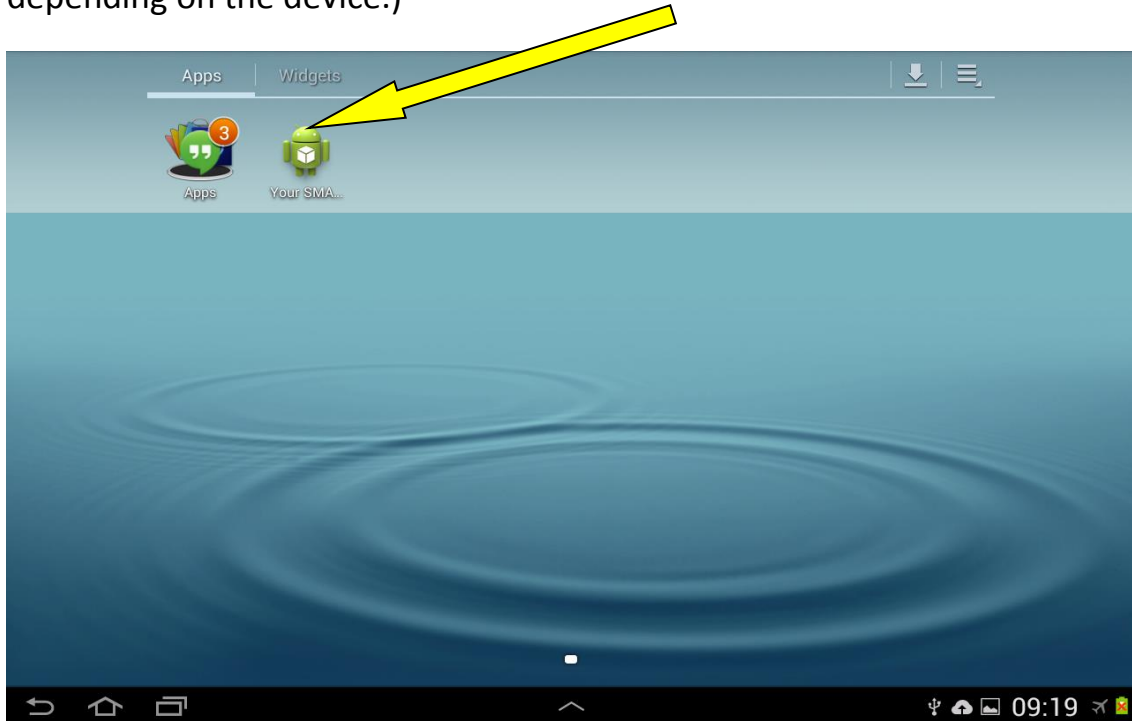
Charger port to charge the tablet. Prior to using the tablet, it's necessary to charge the battery.



Getting started with the app



Find the following green icon on the screen and tap to open the SMART application (Please note, the number of items on the screen may vary depending on the device.)



You should see the screen below. **Slide Down** to find **USERNAME** and **PASSWORD** options (to **slide UP or DOWN**, touch the screen and hold your finger on the screen (ensuring your finger is not on the keyboard) sliding up or down).

Tap on **USERNAME line**, enter your Username. Then tap on **PASSWORD line**, enter your password. When you have entered your **USERNAME** and **PASSWORD**, tap on the **Sign In** button shown in the image below.

Your SMART App

Your Eye Health

Please enter your information in order to access your account.

USERNAME

PASSWORD

Start

Please enter your information in order to create your

18:17

Your SMART App

Your Eye Health

Please enter your information in order to access your account.

USERNAME

PASSWORD

Start

Please enter your information in order to create your

18:17

After successfully signing in, the screen below will appear. Tap on the '**Continue To Your Account**' option.

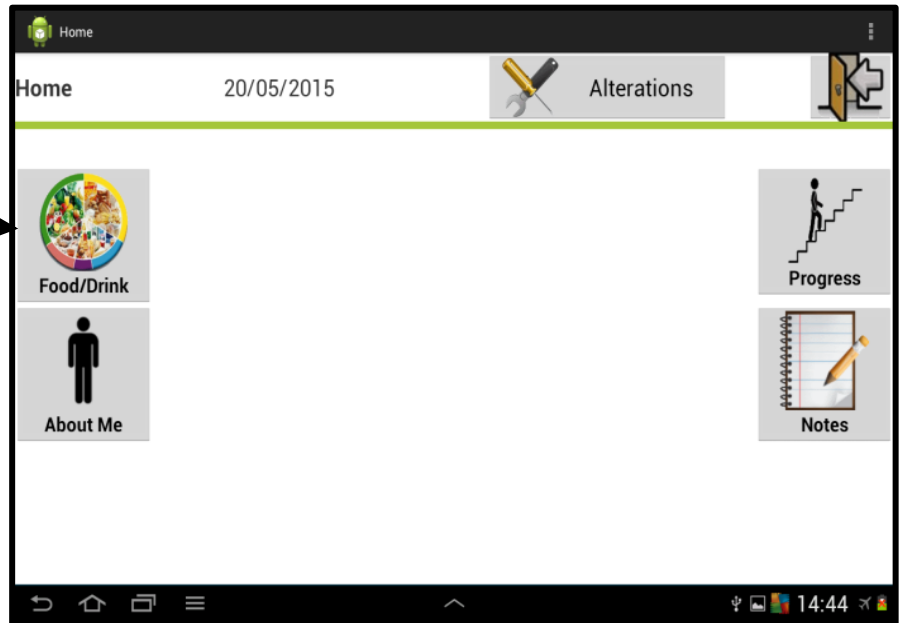
Crossedline

21:51

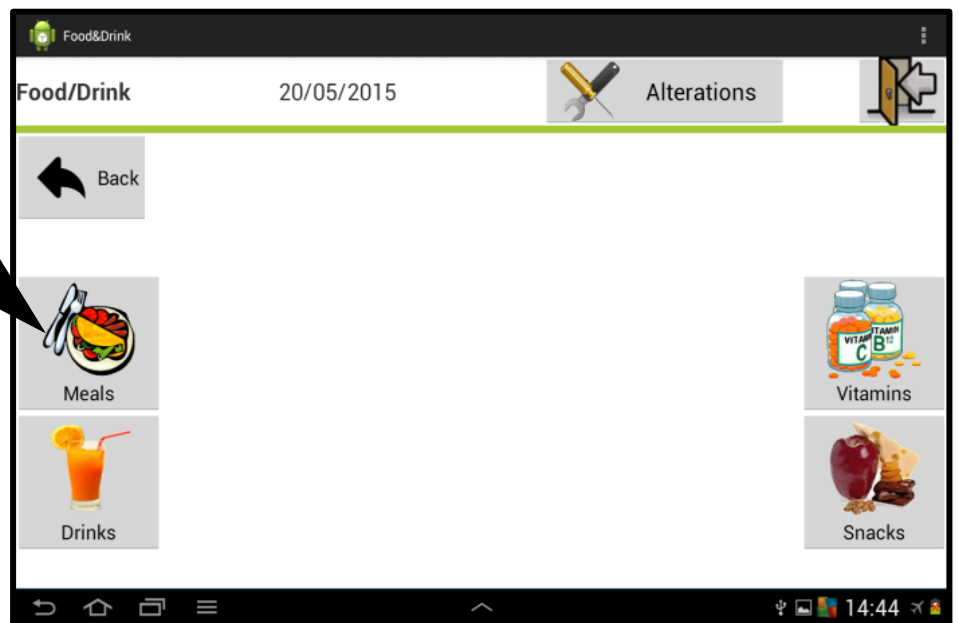
>> Continue To Your Account >>

You will see the **Main Menu** screen below. Here the **FOOD /DRINK** option is for entering your intake of food; **Progress** is for viewing your food entries and recommendations; **About Me** is for recording your disliked food and health conditions; **Notes** is for entering notes; finally, **Alterations** is for altering background colour and text size.

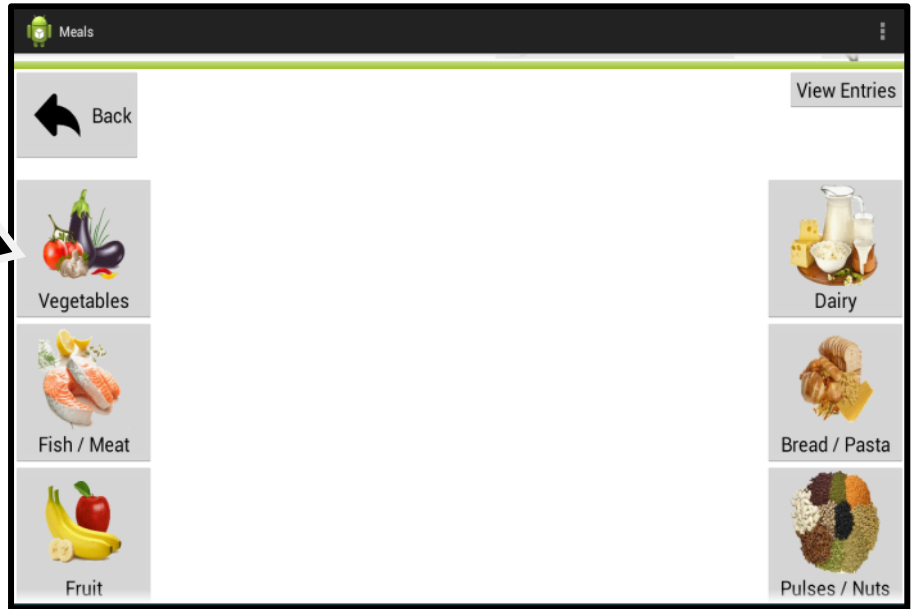
When you tap on the **Food/Drink** option, the screen below will appear.



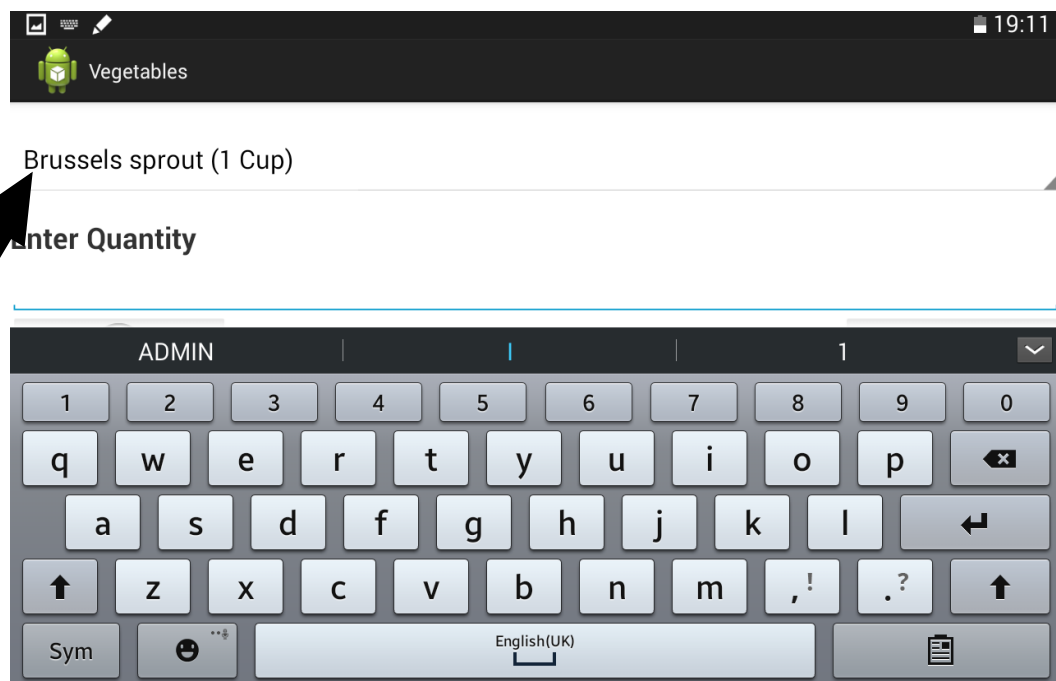
To enter vegetables, for example, tap on the **Meals** option. The screen below will appear.



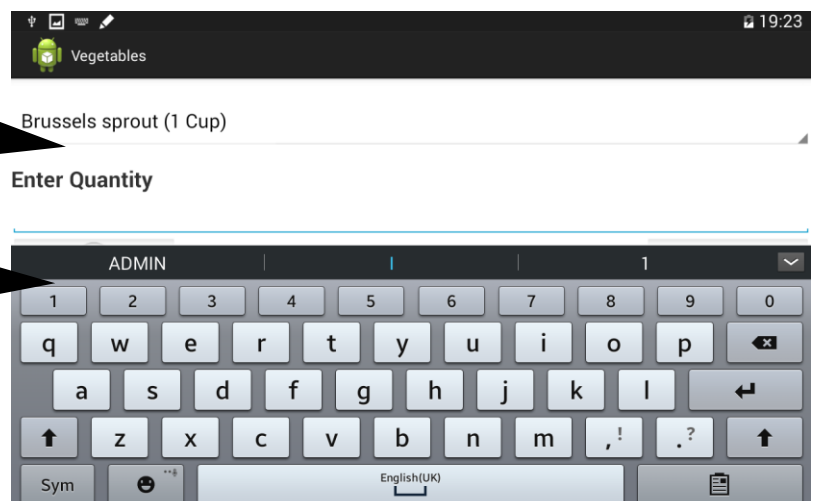
Tap on **Vegetables** option.
The screen below will appear.



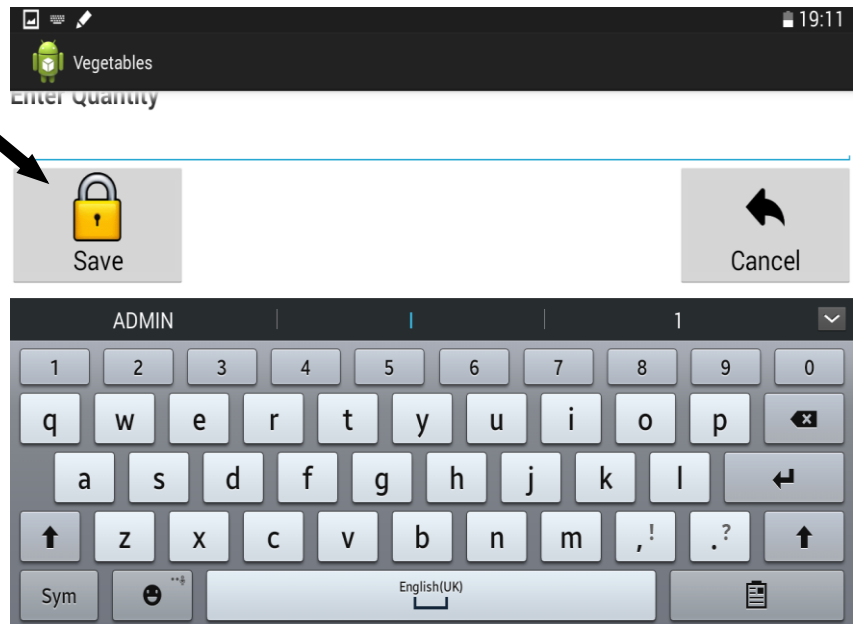
On this screen, tap
on the first line to
select required
vegetable.



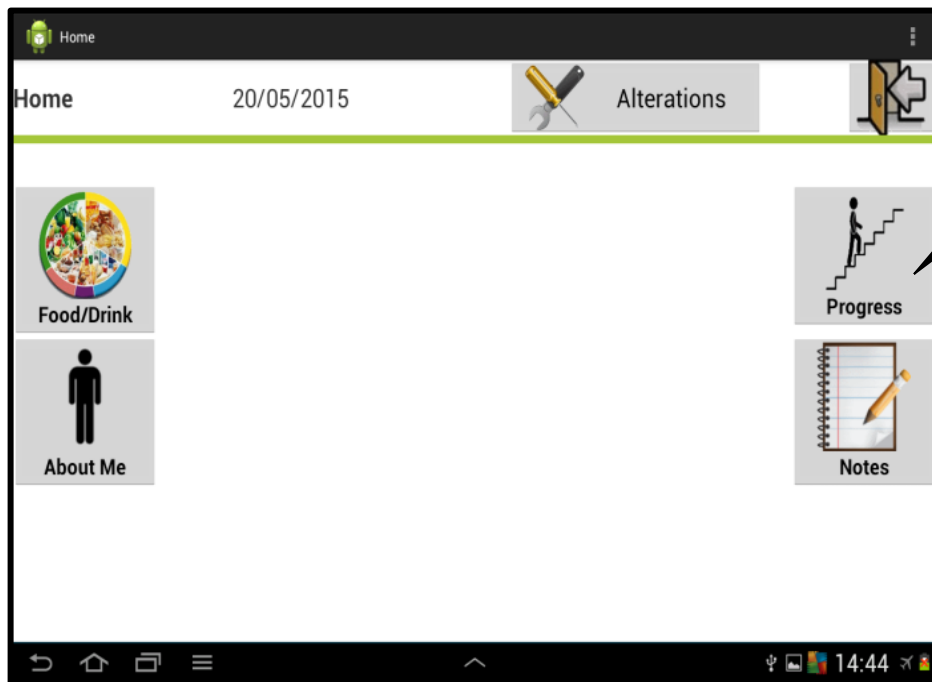
Tap on the **Enter
Quantity**
option and select
quantity from the
keyboard



Tap on the **Save** option to save your selection. Or tap on Cancel option on the right side to go back.

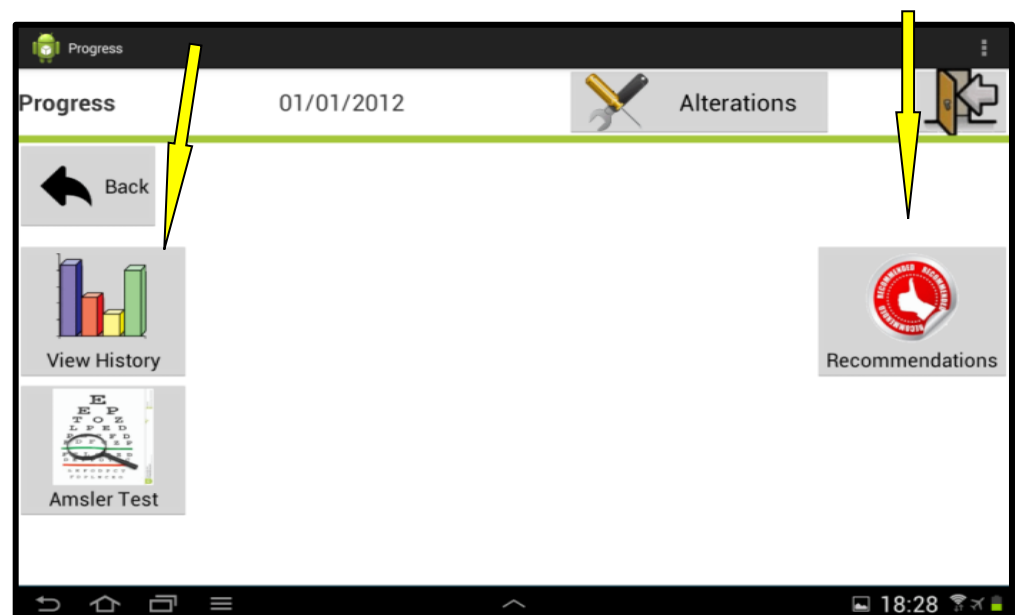


To view your food entries and recommendations tap on the **Progress** option as shown below:

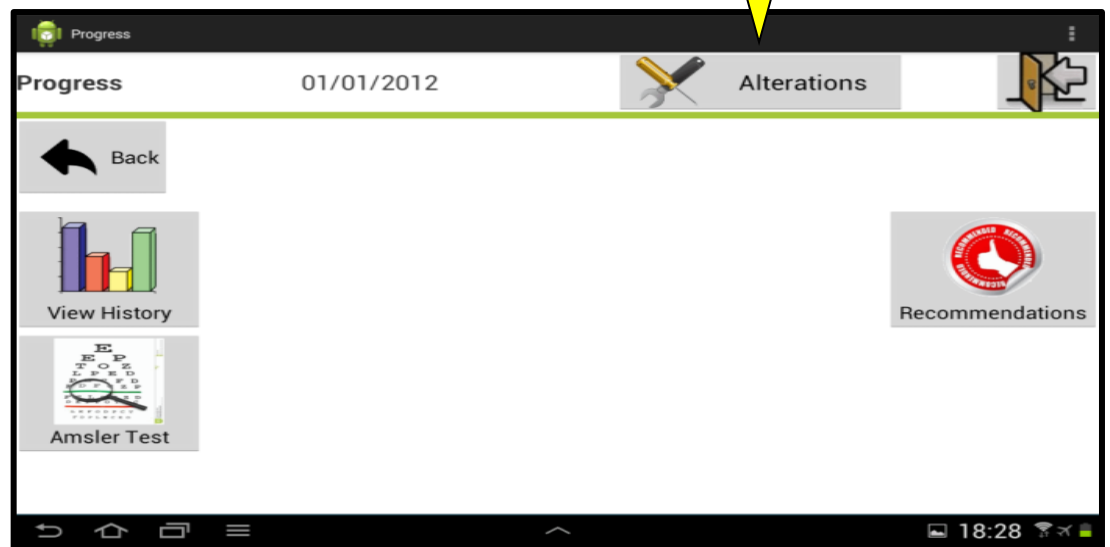


To view your food entries tap on the **View History** option:

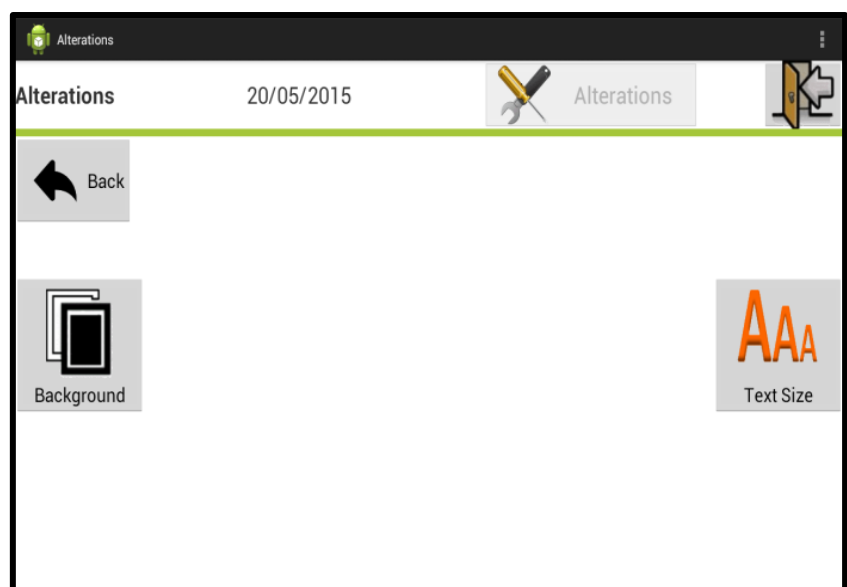
To view your recommendations tap on the **Recommendations**:



To customise the screen tap on the Alterations option as shown below:



And the following screen will appear



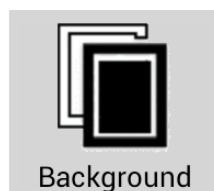
To change text size tap on the Text Size option



Tap on the desired text size to change to that size.

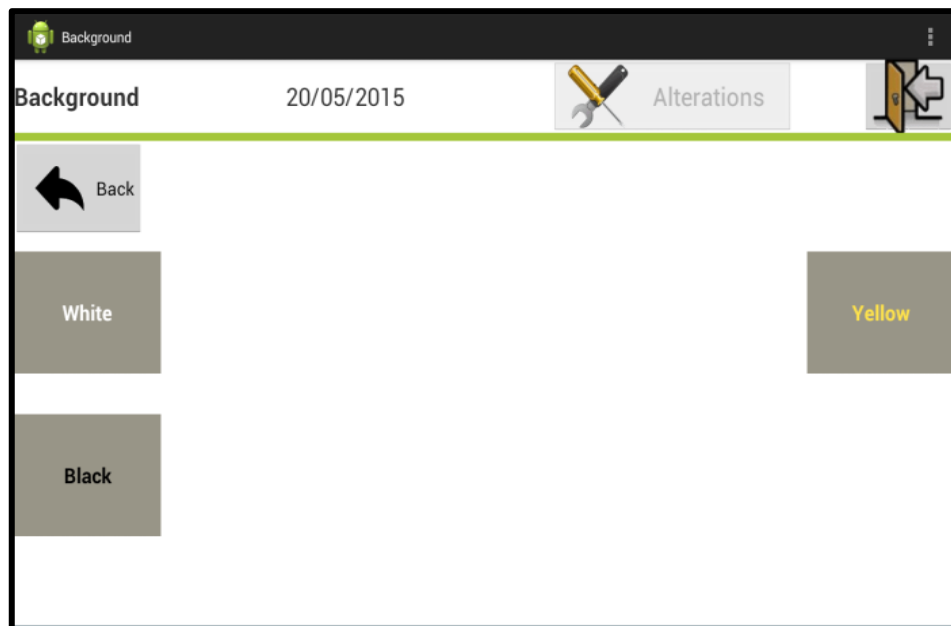


To change the background colour of the app find the following



Background option on previous **Alterations** page.

The following screen will appear – tap on the desired colour to change the background colour to that.



D.6. Phase 6 Study Consent Form

CONSENT FORM

for

participation in the research study entitled:

Developing SMART Technology for Age-Related Macular Degeneration

Please read this consent form carefully and ask as many questions as you like in order to help you decide whether or not to participate in this research study. Your participation is entirely voluntary and there is no penalty or consequence for choosing not to participate. Feel free to discuss your participation in this study with friends, family members, or with other members of your support network. You are free to ask questions at any time before, during, or after your participation in this research. Even if you decide to participate, you are free to withdraw from the study at any time without penalty.

Dear participant,

The purpose of this consent form is to seek your free and informed consent to participate in a research study entitled “*Developing SMART Technology for Age-Related Macular Degeneration*”. Please read and make sure you understand all relevant information provided here before you consent to participate. If anything at all is unclear, please don’t hesitate to discuss this study with Lilit Hakobyan (researcher) or Dr. Joanna Lumsden (chief investigator) whose contact details are included at the end of this form.

1. PURPOSE OF THIS RESEARCH STUDY

You are being asked to participate in a research study designed to evaluate an assistive computer-based mobile application – SMART – designed and

developed with and for persons with Age Related Macular Degeneration (AMD). Scientific evidence suggests that there *may* be a link between nutrition and the onset or rate of progression of AMD. What we have built is a mobile application – that is, a piece of software to run on a tablet device (or similar) – which allows individuals with AMD to accurately and conveniently record what they are eating on a day-to-day basis so that that they can be automatically provided with customised dietary advice in order to empower them to make informed dietary choices which *could* potentially slow down the rate of progression of their AMD.

SMART has been developed by a multidisciplinary team of researchers from computer science, psychology, and clinical optometry **with direct input from people with AMD**, some of whom acted as co-designers for the application itself. It is now really important that we evaluate the use of SMART with its intended user group – people like you. We want to learn from your experience with SMART such that it can be refined to be as good as it can be.

We are asking you to use SMART for a period of 6 weeks as part of your daily routine to help us identify how easy it is to use and determine anything you would like to see changed in the design of the application. We would also like to determine how useful you found it. You will be provided with a tablet device with SMART. We will train you on a one-on-one basis in how to use SMART, set it up to be personalised to your preferences, and then allow you to “play” with SMART so you can get used to it and ask any questions. Once you are happy to proceed, you will be asked to use the tablet device to record your daily food intake so that SMART can give you some suggestions for improving your diet to help you with your AMD.

We will NOT be assessing your diet or judging you on your diet. We will be looking to see whether you used SMART, how easy it was to use, did the

personalisation work for you, and how useful did you find it and the dietary recommendations. In other words, we want to know what YOU thought about the application so that we can improve it so that it *will* work for you.

We will meet with you at the start of the 6 weeks to set things up and again every 2weeks to see how you are getting on using SMART.

Your participation in this study is entirely voluntary and you may end your participation at any time or for any reason without penalty.

Risks

There are no risks associated with participating in this study beyond that of normal, everyday activities.

Confidentiality and Data Storage

All data collected during this study will be kept confidential and will be stored/handled according to the provisions of the UK Data Protection Act 1998. Your responses to any questions will remain anonymous. No one other than members of the research team will have access to the data gathered. Individuals will not be identifiable from the data and will not be identified in any publications related to this research. The data will be stored in a secure fashion.

We thank you very much for your participation.

If you have any questions about this study, please contact us:



or

Dr. Joanna Lumsden (chief investigator)

School of Engineering & Applied Science, Aston University, e-Mail:

j.lumsden@aston.ac.uk, Tel: 0121 204 3470

Consent

I, the undersigned, acknowledge that this study has been explained to me to my satisfaction, and I have been given sufficient time to consider my participation in this study. I confirm that I have received, read, and understood all the information above and give my full and informed consent to participate in the study.

I understand that my participation in this study is entirely voluntary and that I am free to end my participation in the study at any time or for any reason without penalty. I also understand that any member of the research team can end my participation in the study for financial, scientific, or ethical reasons at any time.

I understand that I am being provided with a tablet device for the duration of my participation in this study and that I shall be required to return it upon completion of my involvement in the study.

I understand that by signing this form, I give my full and informed consent to the research team to use the data collected for the purpose of this research and any related research that follows.

Name of the participant:

Signature:

Date: _____

I have explained the study to the above participant and he/she has agreed to take part.

Signature of researcher:

Date: _____

D.7. AMD-Relevant Food Item Examples

AMD Relevant Food Items⁸

Omega 3

The body cannot make omega 3 so it has to be obtained from food, such as oily fish – including salmon, herring, sardines and anchovies – and eggs, meat, milk and cheese.

Lutein

Lutein can be found in yellow and orange peppers, Brussels sprouts, sweetcorn, green peas, mango, bilberries and green leafy vegetables such as kale, all cabbage, winter greens, spinach, chard and broccoli. The vegetables should be cooked as this increases 'bioavailability' (how easy it is for the digestive system to extract the lutein). Kale however, which is by far the best source of lutein, has good bioavailability even without cooking.

Zeaxanthin

Zeaxanthin can be found in orange and yellow fruits, sweet peppers, broccoli, sweetcorn, Romaine lettuce, spinach, tangerines, oranges and eggs. Many of these overlap with food types in which vitamins A, C and E are present.

Antioxidants

The main focus of research into the link between antioxidants and eye health so far has been on vitamins A, C and E. These vitamins help to maintain healthy cells and tissues in the eye and can be found in many different fruits and vegetables such as oranges, kiwis, green leafy vegetables, and tomatoes. They can also be found in nuts, seeds, dairy products and eggs and many other food types. Antioxidants are measured in units called Oxygen Radical Absorbance Capacity (ORAC). This helps identify foods with good antioxidant action. The following foods contain some of the highest amounts of ORAC (it is recommended a minimum of 3,000 ORAC units a day):

| ORAC per 100g | | | |
|---------------------|--------|-----------------|-----|
| Goji Berry | 25,300 | Cherries | 1.8 |
| Prunes | 5,770 | Kiwi fruit | 610 |
| Pomegranates | 3,307 | Pink grapefruit | 483 |
| Raisins/dark grapes | 2,830 | White grapes | 460 |
| Blueberries | 2,400 | Banana | 210 |
| Blackberries | 2,036 | Apple | 207 |
| Cranberries | 1,750 | Apricot | 175 |

⁸ Information sources from the Macular Society: <http://www.macularsociety.org/macular-conditions/>

| | | | |
|--------------|-------|----------------|-----|
| Strawberries | 1,540 | Peach | 170 |
| Raspberries | 1,220 | Pear | 110 |
| Plums | 949 | Watermelon | 100 |
| Oranges | 750 | Honeydew melon | 97 |
| Red grapes | 739 | | |

| Lutein-Zeaxanthin Content of Vegetables (milligrams/100g) | | | |
|--------------------------------------------------------------|------|----------------------------|------|
| Kale | 21.9 | Leaf lettuce | 1.8 |
| Collard greens | 16.3 | Green peas | 1.7 |
| Spinach | 12.6 | Pumpkin | 1.5 |
| Parsley (not dried) | 10.2 | Brussels sprouts | 1.3 |
| Mustard greens | 9.9 | Summer squash | 1.2 |
| Dill (not dried) | 6.7 | Sweetcorn | 0.79 |
| Celery | 3.6 | Yellow pepper (raw) | 0.77 |
| Onions (raw) | 2.1 | Green beans | 0.74 |
| Leeks (raw) | 1.9 | Green pepper | 0.70 |
| Broccoli (raw) | 1.9 | Cucumber pickle/gherkin | 0.51 |
| Broccoli (cooked) | 1.8 | Green olives | 0.51 |

D.8. Phase 6 Study Interview Questions

Interview protocol: discussion was structured around the following sample questions:

E.g., What do you see as the advantages of using the diet diary application?

What do you see as the advantages of following the dietary recommendations?

What do you see as the disadvantages of using the diet diary application?

What comes to your mind when you think about following dietary recommendations?

What comes to your mind when you think about using the diet diary application?

Could you think of people who would approve of you using or think you should use the diet diary application?

Could you think of people who would disapprove of you using or think you should not use the diet diary application?

Who do you think would most benefit from using the diet diary application?

Could you think of any factors or circumstances that would make it easy or enable you to use the diet diary application?

Could you think of any factors or circumstances that would make it easy or enable you to change/alter your dietary behaviour?

Could you think of any factors or circumstances that would make it difficult or prevent you from using the diet diary application?

Could you think of any factors or circumstances that would make it difficult or prevent you from following the dietary recommendations?

How easy was it to use the app?

How often did you use it?

How useful did you find the dietary recommendations?

Do you think you have changed/alter your dietary behaviour in any way?

Did you use the app for anything else other than recording food intake?

| | | | |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Weeks 29th 3 water ✓</p> <p>6 Hot Drinks, cranberries, multi ✓</p> <p>Waffles Pumpkin Seeds, grapes ✓</p> <p>Spiced cheese + salad ✓</p> <p>Chicken, chicken, cashew nuts ✓</p> <p>Cake - almonds ✓</p> <p>Weeks 30th 3 water ✓</p> <p>6 Hot Drinks, grapes ✓</p> <p>Cranberries, pumpkin S. ✓</p> <p>Waffles ✓</p> <p>Brown hazelnut ✓</p> <p>Toasted Almond cake ✓</p> <p>Chicken Broth ✓</p> <p>Semolina + custard ✓</p> <p>2 Rice Ris., 6 almonds ✓</p> | <p>Week 31 3 water ✓</p> <p>6 Hot Drinks, grapes ✓</p> <p>Cranberries, Waffles ✓</p> <p>Pumpkin Seeds, Jam Slices nuts ✓</p> <p>Waffles ✓</p> <p>Semolina, multi, Pesto ✓</p> <p>Semolina, custard ✓</p> <p>2 Rice cakes, 6 almonds ✓</p> <p>NEW ISI SAT</p> <p>3 water ✓ 6 Hot Drinks ✓</p> <p>multi, grapes, waffles ✓</p> <p>bread, bread, pumpkin seeds ✓</p> <p>Cottage cheese + cranberries ✓</p> <p>Chicken, baked beans, Semolina, + Jam ✓</p> <p>2 Rice cakes, 6 almonds ✓</p> <p>1 sm. banana ✓</p> | <p>Week 32 3 water ✓</p> <p>6 Hot Drinks, grapes ✓</p> <p>Cranberries, pumpkin Seeds ✓</p> <p>Waffles ✓</p> <p>Spiced cheese + chicken, fruit ✓</p> <p>Salad, Spiced meat ✓</p> <p>cornish Pasty, Pesto, cabbage ✓</p> <p>caul., Asparagus, custard ✓</p> <p>2 Rice Ris. 6 almonds ✓</p> <p>Week 33 3 water ✓</p> <p>6 Hot Drinks, Bran Flakes ✓</p> <p>grapes, cranberries ✓</p> <p>Waffles, Pumpkin Seeds ✓</p> <p>Cottage cheese + cranberries ✓</p> <p>Salad + chips, banana ✓</p> <p>Custard, 2 Rice Ris., almonds ✓</p> | <p>Week 34 3 water ✓</p> <p>6 Hot Drinks ✓</p> <p>Waffles ✓</p> <p>Cranberries ✓</p> <p>grapes ✓</p> <p>3 Waffles ✓</p> <p>Pumpkin Seeds ✓</p> <p>Ham, chicken, Rice ✓</p> <p>Banana ✓</p> <p>Custard ✓</p> <p>2 Rice Ris. ✓</p> <p>6 almonds ✓</p> |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

- * Minor: no onion skin test.
- * difficult to keep motivated as 'could not access 'progress' lists.
- * I am 'inactivated' daily to check facebook + games - need to 'input' 'food lists' daily.
- * reminder? to enter 'food intake'.
- * tempted to enter 'food' at end of the day - but this negates the purpose of 'supplementing intake'.
- * rather slow process to enter food groups / intake etc.
- * needs colour? / rewards? / sounds? /

~ 332 ~